

Cognitive Training in Patients with Trichotillomania (Hair-pulling Disorder)

by

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Declaration

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Abstract

Background: Hair-pulling disorder (HPD), also known as trichotillomania, is a psychiatric condition characterized by recurrent pulling of hair, resulting in hair loss. Patients report repeated but unsuccessful attempts to reduce or stop the behaviour, leading to significant distress, and in some cases, functional impairment. HPD is characterized by impairments in executive functioning including working memory (WM), impulse control (IC) and emotional regulation (ER). Current interventions include Habit Reversal Therapy (HRT) and pharmacotherapy, but a large proportion of patients do not have access to these treatments or do not respond favourably. An easily accessible strategy in the context of scant resources would be particularly welcome. Based on the efficacy of WM training in improving executive functioning, it was hypothesized that this intervention would 1) be efficacious for reducing the symptoms of HPD, 2) improve compromised neurocognitive functions, 3) and be experienced by patients as an acceptable and feasible method of intervention.

Methods: A single-blind, randomized, 5-week, 25-session cognitive working memory training (CWMT) program versus a control condition was conducted in 30 participants with a primary diagnosis of HPD. The primary outcome measure was the Massachusetts General Hospital Hair-Pulling Scale (MGH-HPS). The control condition required puzzle building, i.e. the *Jigsaw Puzzles* program available on the Internet, following the same 5-week protocol as the CWMT, commercially known as the Cogmed Working Memory Training. Assessments at baseline, immediate post-intervention, and at 3-month follow-up, provided information on clinical and neurocognitive data. Both quantitative and qualitative methods were employed. The quantitative data addressed hypotheses relating to treatment intervention outcomes and were analysed using Statistica 13.3. The qualitative data investigated the experience of living with HPD and addressed the acceptability and feasibility of the intervention and were analysed using Atlas.ti 8.1.30. Statistical analysis of the primary outcome and the neurocognitive data were conducted using mixed model repeated measures analysis of variance (ANOVA). The qualitative data were analyzed using a thematic approach.

Results: CWMT significantly decreased hair-pulling severity compared to the control condition at 5 weeks and 3 months. Although participants did not demonstrate notable impairments in WM compared with norms, WM improved immediately post-training. Although gains in symptoms and WM were maintained at 3 months, there was no longer a significant difference between the cognitive training and control group. There were no impairments in IC and ER at baseline, and CWMT did not have greater impact on IC and ER than the control condition. Qualitatively, participants indicated that CWMT was feasible and acceptable; furthermore, participation in the study was associated with greater openness about symptoms at home, feeling less isolated, and feeling more supported.

Conclusions: This is the first study of CWMT in HPD and demonstrates not only the feasibility and acceptability of this intervention, but also its efficacy. Further work is needed to study the relevant mechanisms, and to assess the effectiveness and cost-efficiency of this intervention in larger pragmatic trials aimed at scaling-up the intervention.

Abstrak

Agtergrond: Haar-uittreksteuring (HUS), ook bekend as trichotillomanie, is 'n psigiatryse toestand gekenmerk deur die herhaaldelike uittrek van hare, gepaardgaande met haarverlies. Pasiënte rapporteer herhaaldelike maar onsuksesvolle pogings om die gedrag te verminder of te stop, wat lei tot beduidende distres en, in sommige gevalle, funksionele inperking. HUS word gekenmerk deur probleme in uitvoerende funksies, insluitend werksgeheue (WG), impulsbeheer (IB) en emosie-regulering (ER). Huidige intervensies sluit in “Habit Reversal Therapy” (HRT) en farmakoterapie, maar 'n groot hoeveelheid pasiënte het nie toegang tot hierdie behandelings, of reageer nie gunstig daarop nie. 'n Maklik toeganklike strategie in die konteks van beperkte bronne sal verwelkom word. Gebaseer op die doeltreffendheid van WG-opleiding in die verbetering van uitvoerende funksies, is die hipoteses gestel dat hierdie intervensie 1) doeltreffend sal wees vir die vermindering van simptome in HUS, 2) spesifieke neurokognitiewe funksies sal verbeter, en 3) deur pasiënte ervaar sal word as 'n aanvaarbare en haalbare intervensie-metode.

Metodes: 'n Enkel-blinde, ewekansige, 5-week, 25 sessie kognitiewe werksgeheue-opleidingsprogram (KWGO) versus 'n kontrole-intervensie, is uitgevoer met 30 deelnemers met 'n primêre diagnose van HUS. Die primêre uitkoms-instrument was die “Massachusetts General Hospital Hair-Pulling Scale” (MGH-HPS). Die kontrole-intervensie het legkaartbou naamlik die “*Jigsaw Puzzles*” program, beskikbaar op die Internet, behels, wat dieselfde 5-weke protokol gevolg het as die KWGO, kommersieël bekend as “Cogmed Working Memory Training”. Evaluering by basislyn, onmiddellik post-intervensie, en tydens 3-maande-opvolg het inligting oor kliniese en neurokognitiewe data voorsien. Beide kwantitatiewe en kwalitatiewe metodes is gebruik. Die kwantitatiewe data het die hipoteses verwant aan die behandelingsuitkomstes aangespreek, en is geanaliseer met behulp van Statistica 13.3. Die kwalitatiewe data het die ervaring van om te lewe met HUS ondersoek en die aanvaarbaarheid en haalbaarheid van die intervensie aangespreek en is geanaliseer met behulp van Atlas.ti 8.1.30. Statistiese analise van die primêre uitkoms en die neurokognitiewe data is uitgevoer deur gebruik te maak van die gemengde-model herhaalde

metings “analysis of covariance” (ANOVA). Die kwalitatiewe data is geanaliseer deur gebruik te maak van die tematiese benadering.

Resultate: KWGO het haar-uittrek-simptome beduidend verminder in vergelyking met die kontrole-intervensie by 5 weke en 3 maande. Alhoewel deelnemers nie merkbare probleme in WG demonstreer het in vergelyking met die norm nie, het WG onmiddellik post-opleiding verbeter. Alhoewel verbetering in haar-uittrek-simptome en WG behou is by 3 maande, was daar nie meer ‘n beduidende verskil tussen die opleidingsgroep en die kontrolegroep se prestasie nie. Daar was geen probleme met IB en ER by basislyn nie, en KWGO het nie ‘n groter impak op IB en ER as die kontrole-intervensie gehad nie. Kwalitatief geassosieer, het deelnemers aangedui dat KWGO aanvaarbaar en haalbaar was en ook dat die deelname aan die studie geassosieer was met meer openlikheid tuis oor simptome, en het gevoelens van verminderde isolasie en verhoogde ondersteuning teweeg gebring.

Gevolgtrekkings: Hierdie is die eerste studie van KWGO in HUS en demonstreer nie net die aanvaarbaarheid en haalbaarheid van die interventie nie, maar ook die doeltreffendheid daarvan. Verdere werk word benodig om die relevante meganismes hiervan te bestudeer, en om die doeltreffendheid en koste-effektiwiteit van hierdie interventie te assesser met groter pragmatiese studies wat verbetering van die interventie ten doel het.

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“The process is really demoralizing and then you get stuck thinking, ‘well that is it for life.’ It is never going to go, I am never going to be able to fix it...”

Research Participant

Chapter 1: Background

Introduction

Hair-pulling disorder (HPD), also known as trichotillomania, is a condition in which patients engage in recurrent pulling of hair, resulting in hair loss. The French dermatologist Hallopeau coined the term *trichotillomania*, over a century ago (Hallopeau, 1889), which is derived from ‘*Trich*’, the Greek word for ‘hair’; ‘*tillein*’ meaning ‘to pull’ and ‘*mania*’, meaning ‘being mad’ (Merriam Webster Online Dictionary, 2018). The participant quote on the previous page, provides but a glimpse of the experience of life with HPD almost 130 years later. Previously included in the impulse-control disorders not elsewhere specified (American Psychiatric Association, 2000), HPD is now classified as an obsessive-compulsive related disorder in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), (American Psychiatric Association, 2013). HPD criteria include hair loss linked to continuous pulling, as well as repeated attempts to decrease or stop the pulling. The behaviour causes significant distress or impairment in multiple important areas of functioning, and the symptoms are not caused or better explained by another medical condition or mental disorder (American Psychiatric Association, 2013a).

A ratio of 10:1 for females versus males has been noted in adults with HPD (American Psychiatric Association, 2013; Christenson, MacKenzie, & Mitchell, 1994; Lochner et al., 2005). The average age of onset for HPD is 12 years (Christenson, MacKenzie, & Mitchell, 1991; Cohen et al., 1995; Lochner et al., 2005; Walsh & McDougle, 2001; Winchel, 1992), and the prevalence of HPD in a 12-month period has been estimated at between 1 and 2% (American Psychiatric Association, 2013).

Patients live with the constant awareness of the impact of their symptoms on self and others in areas of social, occupational, academic and family functioning (Diefenbach, Mouton-Odum, & Stanley, 2002; Seedat & Stein, 1998; Stemberger, Thomas, Mansueto, & Carter,

2000). In an internet-based survey completed by 1697 participants, the entire sample reported their life impairment in above mentioned areas of functioning as mild to moderate (Woods, Flessner, et al., 2006). It was further noted that the more severe the hair-pulling symptoms, the more severe the impairment reported. The negative impact of HPD on individuals' lives should not be underestimated (Harvard Health Commentaries, 2007; Seedat & Stein, 1998; Tung, Flessner, Grant, & Keuthen, 2015; Woods, Wetterneck, & Flessner, 2006). For example, HPD is associated with problematic triggering events (family conflict, chronic illness, harassment, stressful times), negative affect (isolation, embarrassment and shame, anger and frustration fear, guilt, humiliation and pain, body image issues) and control difficulty (deciding to whom and when to self-disclose, lack of information from the medical community may cause the feeling of not being in control of treatment and lack of control of the pulling behaviour) (Casati, Toner, & Yu, 2000; Johnson & El-Alfy, 2016; Whitaker, Wolf, & Keuthen, 2003).

Patients are often well-functioning members of society who hide their diagnosis of HPD well and many have comorbid mood, anxiety, substance and obsessive-compulsive disorders which might complicate their lives further (Christenson et al., 1994; Winchel et al., 1992). Major depressive disorder and excoriation (skin-picking) disorder seems to accompany HPD more often, while repetitive body-focused behaviour also occur in most patients with HPD (American Psychiatric Association, 2013a). Comorbid depression in HPD has shown to have a specific influence on these patients' quality of life (Houghton et al., 2016). These comorbid disorders can often be the primary focus of attention, with HPD often not highlighted as a clinical diagnosis of its own. Houghton et al., (2016) found that 38.8% of individuals with HPD diagnosis in their study had another current psychiatric diagnosis, and 78.8% have had a diagnosis of mental illness at some time (present and/or past) during their lives. Awareness is critical in supporting members of the community, who are valuable to the job market, to look after their mental health before getting to a place of mental illness where they are no longer able to function optimally. Patients often avoid accessing health care services

due to feelings of shame (Singh, Wetterneck, Williams, Knott, & Memorial, 2016; Stemberger et al., 2000; Weingarden & Renshaw, 2014; Whitaker et al., 2003), which contributes to delays in treatment seeking, incorrect diagnosis and reduced quality of life (Adaletli et al., 2016; Seedat & Stein, 1998; Woods, Flessner, et al., 2006). Delays in help-seeking increase the possibility that comorbid psychiatric difficulties may arise (Adaletli et al., 2016), highlighting the importance of early intervention.

Now that we know a bit more about HPD – what the symptoms are, who suffers from it and why it is not readily recognized, we turn our attention to aetiological explanations thereof.

Aetiology of HPD

There are several different theories and models to explain the aetiology of HPD. For example, an Ethological Model suggests that hair-pulling behaviour can be related to excessive grooming (Swedo, 1989; Swedo & Rapoport, 1991). A Biopsychosocial Model (Franklin, Tolin, & Diefenbach, 2006) makes the following core assumptions: behaviours are the outcome of stressors experienced and a response to internal or external forces; current situations carry more weight in understanding the behaviour than past experiences; and at the core of hair-pulling behaviour is an interaction of physiological characteristics, thoughts and feelings, and consequences of the behaviour itself. The model further suggests biological vulnerability, altered pain sensitivity, behavioural triggers, reinforcement and delayed consequences of the hair-pulling, and thus highlights the fact that the disorder is multifaceted. Although not excluding ethological and biological components, the Cognitive Control Model (A-B-C Model) states that affect regulation, behavioural addiction and cognitive control are at the core of the difficulties experienced (Stein, Chamberlain, & Fineberg, 2006). Another model suggests that affective dysregulation plays an important part in developing and maintaining the hair-pulling symptoms (Flessner, Knopik, & McGeary, 2012; Keuthen et al., 2010; Shusterman, Feld, Baer, & Keuthen, 2009) while the Stimulus Regulation Model (Penzel, 2018) states that people pull when they are either over- or under

stimulated, and may thus be linked to a genetic predisposition to effectively manage internal sensory imbalance in an external manner. Grooming-type behaviour is ideal for reducing or producing stimulation, under which hair-pulling will also fall. The Comprehensive Model of Trichotillomania (TTM), states that no one model could ever fully explain HPD and that treatment should speak to all the various inputs, internally and externally, that may lead to HPD. The interaction between four internal modalities, i.e. cognitive, affective, motoric and sensory, and one external modality, the environmental factors, all play a role in understanding HPD (Mansueto, Golomb, Thomas, & Stemberger, 1999).

Although these are all distinct models, they do appear to be quite similar in viewing the patient holistically and being comprehensive in explaining the hair-pulling behaviour.

HPD Treatment Overview

Various treatment avenues have been developed and followed to treat HPD. This section takes a closer look at these treatment possibilities. Treatments address symptoms of HPD but also aim to improve associated distress and impairment in work, family and social relationships, self-esteem and health (Diefenbach, Tolin, Hannan, Crocetto, & Worhunsky, 2005; Tung et al., 2015). HPD treatment research was given impetus by work on Obsessive-Compulsive and Related Disorders (OCDs) such as OCD, and there are both psychological interventions as well as pharmacological agents available that may be of value in HPD (Slikboer, Reser, Nedeljkovic, Castle, & Rossell, 2018). This study focused on adults (individuals 18 years and older) with HPD, and the review thus excludes interventions for children and adolescents.

Pharmacotherapy

In terms of pharmacotherapy, several treatments have been developed and investigated. N-acetylcysteine (NaC) (Grant, Odlaug, & Kim, 2009; Odlaug & Grant, 2007), clomipramine (Ninan, Rothbaum, Marsteller, Knight, & Eccard, 2000; Swedo, Rapoport, Lenane,

Goldberger, & Cheslow, 1989) and olanzapine (Van Ameringen, Mancini, Patterson, Bennett, & Oakman, 2010) show promise in RCTs, but further replication studies are required. Citalopram showed significant improvement in an open-label naturalist study (N = 14) (Stein, Bouwer, et al., 1997). Although further RCTs are warranted, several small open-label studies showed promise for haloperidol (Van Ameringen, Mancini, Oakman, & Farvolden, 1999), topiramate (Lochner et al., 2006), dronabinol (Grant, Odlaug, Chamberlain, & Kim, 2011) and aripiprazole (White & Koran, 2011). Other medications, such as SSRIs i.e. fluoxetine and sertraline (Rothbart et al., 2013; Streichenwein & Thornby, 1995; Van Minnen, Hoogduin, Keijsers, Hellenbrand, & Hendriks, 2003), and naltrexone (Rothbart et al., 2013), showed no significant effect in the treatment of HPD or only showed efficacy in a HPD patient subgroup (Gadde, Ryan Wagner, Connor, & Foust, 2007; Stanley, Breckenridge, Swann, Freeman, & Reich, 1997). Inositol did not show any significant effect in a double-blind placebo-controlled trial (Leppink, Redden, & Grant, 2017).

When patients present with poor response to cognitive behavioural therapy (CBT), medication is often added as augmentation (Flessner, Penzel, & Keuthen, 2010). In studies comparing CBT with fluoxetine (Van Minnen et al., 2003) and clomipramine (Ninan et al., 2000), CBT was found to be significantly more effective than medication. In a study of sertraline alone versus sertraline with add-on habit reversal therapy (HRT), combined pharmacotherapy and psychotherapy treatment showed significantly better gains than medication only (Dougherty, Loh, Jenike, & Keuthen, 2006).

At the time of submission of the dissertation, The Food and Drug Administration (FDA) has not yet approved any medication for HPD treatment (Huynh, Gavino, & Magid, 2013; Johnson & El-Alfy, 2016).

Psychotherapy

Several psychotherapies have been developed and investigated as possible psychological treatments for HPD. These interventions include behaviour therapy (BT) (Boughn & Holdom, 2002; Diefenbach, Tolin, Hannan, Maltby, & Crocetto, 2006; Falkenstein, 2013; Van Minnen et al., 2003), HRT (a type of CBT) (Azrin, Nunn, & Frantz, 1980; Bloch et al., 2007), CBT enhanced with dialectical behavioural therapy (DBT) and acceptance and commitment therapy (ACT) (Keuthen et al., 2011, 2012; Twohig & Woods, 2004; Woods, Wetterneck, et al., 2006). In the following section, data from the evidence-based psychological treatments for patients with a primary diagnosis of HPD will be briefly reviewed.

BT techniques are the cornerstone of many psychotherapy treatments for HPD symptoms and in general focus on the motor aspect of pulling (Azrin & Nunn, 1973). BT includes self-management in the form of self-monitoring, covert desensitization, HRT and therapist management of behavioural techniques in the form of reward and punishment (Friman, Finney, & Christophersen, 1984). Very closely linked to BT, is CBT. The cognitive component of CBT emphasizes that distorted thoughts have a central role and that if these can be modified and thinking be made more realistic, there will be an improvement in symptoms (Beck, 1995). CBT based therapies were reported to have a large success rate in HPD treatment when examining the view of treatment practices of members of the Trichotillomania Learning Center-Scientific Advisory Board (TLC-SAB) and other experienced clinicians (Flessner et al., 2010). Taking a closer look at specifically which components of CBT was highlighted for treatment of adults, awareness training, self-monitoring, competing response training, HRT and stimulus control were ranked in descending order of use. According to Rehm, Moulding, and Nedeljkovic (2015), a distinction needs to be made between traditional CBT and enhanced CBT, i.e. CBT developed specifically for the treatment of HPD, as these authors stated that research on the effect of traditional CBT on HPD is still unclear and not well investigated. HPD studies in which CBT

focused on mood regulation were compared to those where CBT focused only on hair-pulling, and presented the evidence that the prior is superior to traditional CBT regarding effect size, and that the number of therapeutic hours correlated positively with the outcome of effect sizes in the treatment of HPD (McGuire et al., 2014).

HRT comprises a set of BT techniques and has been studied for HPD for many decades (Azrin et al., 1980; Morris, Zickgraf, Dingfelder, & Franklin, 2013). Based on data showing efficacy, HRT has been encouraged as a first line intervention for HPD (Bloch et al., 2007; Chamberlain, Odlaug, Boulougouris, Fineberg, & Grant, 2009; Duke, Keeley, Geffken, & Storch, 2010; Flessner et al., 2010). This intervention investigates the patient's specific hair-pulling behaviour and employs specific BT techniques to address symptoms including reversal of the positive reinforcement of pulling behaviours (Morris et al., 2013). HRT includes awareness training, using competing reactions, identification of response precursors, as well as self-monitoring, stimulus control procedures, competing responses, relaxation training, keeping a journal of hair-pulling, prevention training, as well as habit interruption and positive attention (Azrin et al., 1980; Flessner et al., 2010; Morris et al., 2013; Woods & Miltenberger, 1995). The ultimate goal is for the patient to recognize and deal with situations in which urges may occur more readily, as well as using other techniques instead of the pulling behaviour (Morris et al., 2013). Despite the efficacy of HRT, many individuals do not show a sustained response (Rehm et al., 2015).

Another type of HRT, Decoupling, a technique of interfering with the physical motor movement of hair-pulling, showed significant benefit in HPD compared to progressive muscle relaxation (PMR) (Moritz & Rufer, 2011). Decoupling mimics the initial movement but changes the motor movement to a more appropriate action. When comparing HRT with fluoxetine and waiting-list controls, no gain maintenance was shown during a 2-year follow-up (Van Minnen et al., 2003). There has been some indication in HRT that an 8-week maintenance phase of individual contact sessions and phone calls, after active treatment,

can play a role in relapse prevention (Franklin & Tolin, 2007; Franklin, Zagarbe, & Benavides, 2011). There appears to be a need for more RCTs monitoring the efficacy of HRT especially with regards to long-term outcome, in the literature.

Given the evidence for the partial efficacy of HRT, several studies have investigated ways of augmenting this modality. It has been proposed that HRT should be enhanced with techniques such as Acceptance and Commitment Therapy (ACT), Dialectical Behaviour Therapy (DBT) and other non-traditional modalities, as will be discussed in the next section.

ACT enhanced HRT combines elements of both HRT and ACT. The main goal of ACT is relapse prevention (Woods, Wetterneck, et al., 2006), and it focuses on mindfulness, values work and defusing thoughts literally interpreted (Crosby, Dehlin, Mitchell, & Twohig, 2012; Rehm et al., 2015; Twohig & Woods, 2004; Woods, Wetterneck, et al., 2006). This specific modality showed success in reducing symptoms at 3-month follow-up (Twohig & Woods, 2004; Woods, Wetterneck, et al., 2006) in a randomized trial of waiting-list control versus ACT enhanced HRT. In another study using the same treatment combination, significant initial benefit was shown post-treatment, but over half of participants lost treatment gains at 3-month follow-up (Crosby et al., 2012). As with un-enhanced HRT, more RCTs are needed to investigate the efficacy of ACT enhanced HRT.

DBT enhanced HRT is another type of adapted HRT which includes skills training and emotional regulation (ER) strategies (Morris et al., 2013). DBT-enhanced HRT also showed a significant reduction in baseline HPD symptoms in 3- and 6 months follow up but was not compared to an active control group. In this study symptom reduction correlated with improvements in emotional control (Keuthen et al., 2011). DBT-enhanced HRT was found to have a significant improvement in the severity of HPD, ER, anxiety and depression and experiential avoidance compared to minimal attention control condition. It was also noted that the gains were maintained at 6-month follow-up (Keuthen et al., 2012). Longer treatment duration, as well as increased focus on maintenance issues at the end of treatment (through

booster sessions or increasing the time period between the last few sessions), may aid patients in maintaining their gains (Woods et al., 2006).

The Comprehensive Behavioural Model (ComB) is a 10-step model of treatment that takes sensory, cognitive, affective, motor and place modalities into consideration (Mansueto, Golomb, Thomas, & Stemberger, 1999; Stemberger, Stein, & Mansueto, 2003). In an uncontrolled study, the model showed a large decrease in HPD symptoms and impairment, but still needs to be investigated in an RCT (Falkenstein, Mouton-Odum, Mansueto, Golomb, & Haaga, 2016). Metacognitive techniques, i.e. detached mindfulness and ritual postponement, combined with HRT (MCT/HRT) also showed significant efficacy in the treatment of HPD compared to waiting list control (Shareh, 2018).

Although individual therapy is the most used treatment modality for adults and children with HPD (Flessner et al., 2010), group therapy may also show benefit. The positive feature of the group therapy is that multiple patients can receive treatment simultaneously. The other benefit of group therapy is that group members can connect with others that may be going through similar challenges and experiencing similar themes of shame and stigmatization (Weingarden & Renshaw, 2014). Group CBT was found to have better efficacy in addressing hair-pulling symptoms compared to supportive group therapy (Toledo, De Togni Muniz, Marcelo Cabrita Brito, Nabuco de Abreu, & Tavares, 2015). Another RCT, comparing group BT to supportive group therapy noted significant initial gains for the BT group. However, these gains were not maintained at 1, 3 or 6-month follow-up (Diefenbach, Tolin, Hannan, Maltby, & Crocetto, 2006). Although not a trial study, on examining group intervention experience - a sample of women (N=44) reported that they found internet HPD groups and HPD support groups beneficial (Boughn & Holdom, 2002). A recent ACT-enhanced BT group therapy study showed promise in reducing symptoms when assessed immediately post-treatment (90% of participants), as well as at 1-year follow-up (6% of participants), but there was no control (Haaland et al., 2017). A goal for future research would be investigating

individual therapy compared to group therapy, as according to our knowledge, this has not been investigated.

These different types of therapies mostly follow the same mode of delivery – i.e. face-to-face or in-person clinician-patient treatment or therapeutic interaction. One of the challenges of most existing evidence-based treatment approaches is that these are not always available, accessible or affordable. Internet-based and mobile application interventions may be a way to address these challenges. The TLC Foundation for Body-Focused Repetitive Behaviors (“Find Online/Other Services - The TLC Foundation for BFRBs,” n.d.) provide many useful resources on HPD. The online HPD treatment interventions that do exist include TrichStop (“TrichStop.com | Online Trichotillomania Center,” n.d.) and StopPulling.com (“Stop Pulling,” n.d.). None of these have been comprehensively tested in RCTs. Nevertheless, one case study reported that online therapy comprising of HRT and REBT, reduced hair-pulling (Onrust & Nunic, 2016). Another study, investigated ACT-enhanced BT delivered via telepsychotherapy, and showed a significant decrease in symptom severity compared to waiting-list control, which was maintained at follow-up (Lee, Haeger, Levin, Ong, & Twohig, 2018). 265 users, who utilized StopPulling.com, reported an improvement in symptoms of hair-pulling (Mouton-Odum, Keuthen, Wagener, & Stanley, 2006). A survey done on internet support groups for patients with HPD found that online support is helpful in creating awareness and knowledge of the illness (Bruwer & Stein, 2005). It is thus encouraging that new treatment avenues such as web-based or electronic interventions are starting to emerge, but there is a lack of evidence from controlled trials to support these treatments.

In conclusion, this section provided an overview of HPD and the therapeutic modalities used in its treatment. Studies of a range of pharmacotherapy and psychotherapy interventions have found varying degrees of efficacy. Based on systematic reviews of this work, treatment guidelines have recommended HRT, and there is work showing that this can be enhanced with ER or mindfulness-based therapies, like ACT or DBT. Treatment guidelines have also suggested that augmenting therapy with medication may be useful in certain circumstances

e.g. when comorbid depression is present (Flessner et al., 2010). One of the challenges of evidence-based psychotherapies for HPD is that these are not available, accessible or affordable in all contexts. Attending sessions can be costly, regarding both time and finances. Access to mental health services can be challenging, especially in a country like South Africa, where there are relatively few mental health professionals and where basic health care services are under huge pressure (Petersen & Lund, 2011; Ramlall, 2012; Skeen et al., 2010).

In the following section, the challenges of treatment for HPD in the South African context are further highlighted in motivating for a novel intervention for addressing HPD and related issues, to be introduced.

Problem Statement

South African research presents with many studies on HPD, but with minimal focus on treatment interventions (Lochner et al., 2006). In general, there are many barriers to mental health care in the country, which can also influence the treatment of HPD. Barriers to investigating an appropriate and feasible intervention for HPD are considered.

Burns (2011) highlighted several barriers to mental health services in South Africa – psychiatric hospitals are unfit for service provisions, there are shortages of mental health professionals, as well as a shortfall of tertiary level psychiatric services, and underdeveloped rehabilitation services. Mental health and psychotherapeutic support might not be readily available or accessible to most people in low- and middle-income countries such as South Africa (Burns, 2011; Goldstone & Bantjes, 2017; Hanlon, Wondimagegn, & Alem, 2010; Lund, Kleintjes, Kakuma, & Flisher, 2010; Petersen & Lund, 2011; Ramlall, 2012; Skeen et al., 2010). Indeed, in such contexts the physical distance from mental health centres can be challenging as most clinics are in urban centers, which greatly influences access to mental health care (Lund et al., 2010; Tomita et al., 2017). Public transport is still being developed

in South Africa and although great strides have been made, there is still a lack of services in many communities (Frankson, 2015; Walters, 2014). This situation affects many individuals, whose only option then is to walk great distances or use unsafe or unreliable public transport.

When turning to government supported mental health services, waiting lists are long and the treatment usually comprise short-term interventions. Jack et al. (2014) highlighted the significant treatment gap in in mental health services, especially in the rural areas. Taking into consideration that current HPD treatment is quite specialized, the chance of accessing specific evidence-based treatment in this type of setting is unlikely (Burns, 2011; Lund et al., 2010; Marais & Petersen, 2015). Apart from the cost of services, time off work is another consideration. If one considers attending treatment may mean time off work for consultations, travel time, as well as the cost of travel – it seems less and less viable for a patient to attend weekly treatments for HPD.

Considering these obstacles to accessing evidence-based treatment for HPD in the South African context, the responsibility lies with mental health providers to find a treatment solution that can bypass these hurdles (Hanlon et al., 2010).

Brief Chapter Overview

Chapter 1 (Introduction) described HPD and the impact of the disorder on patient functioning as well as providing a broad overview of treatment options. It aimed to introduce the reader to various dilemmas faced by patients with HPD, as well as provide an overview of available treatments and why it is important to investigate novel treatment approaches.

In addition to HPD, its associated features and sequelae, patients with HPD face other challenges as well. These include various executive functioning difficulties, more specifically working memory (WM), impulse control (IC) and emotional regulation (ER) which will be teased out in **Chapter 2 (Literature Review)** and used to provide a rationale for the

proposed treatment investigated in this study. **Chapter 3 (Aims and Hypotheses)** provides an overview of the aims and hypotheses the research study wishes to answer. In **Chapter 4 (Methodology)** the research design and methods; research instruments; data analysis and collection; as well as ethical considerations will be covered. **Chapter 5 (Results: Quantitative Data)** and **Chapter 6 (Results: Qualitative Data)** will provide data collected during the process, using research instruments and interviews. **Chapter 7 (Discussion)** will discuss and link the findings to existing knowledge in the field of HPD, while providing an overview of project limitations and recommendations for future research.

“You go through these like days where you can, where you can like feel like you can deal with it and then there are other days when you just go into, almost like a dark place, h’m, because you feel like so disappointed in yourself that you like ask yourself a question like: “Really like why can’t you just like ruk jouself reg?”

Research Participant

Chapter 2: Literature Review

Introduction

The previous chapter provided a review of various therapeutic possibilities for HPD. It was seen that treatment is not readily accessible around the world, and this is even more so in low- or middle-income countries such as South Africa.

It would be important to understand the underlying mechanisms of hair-pulling. Highlighting these additional challenges and linking it to evidence-based treatments in disorders with similar deficits, could suggest a treatment novel to HPD and worthy of investigation.

This chapter provides an overview of the most salient neurocognitive challenges associated with HPD and links findings to the rationale behind the treatment trialed here.

Neurocognitive Challenges in Hair-pulling Disorder

BFRBs, including HPD, have shown difficulty in executive functioning (Flessner, Francasio, Murphy, & Brennan, 2015). A review article reporting on neurocognitive modalities showed statistical significant deficits in patients with HPD, regarding processing speed, divided attention, visual memory and working memory (WM), executive functioning and motor response inhibition (Slikboer et al., 2018).

Findings on executive functioning and other neurocognitive difficulties in HPD will be discussed next. The review here focuses on controlled studies and systematic reviews. This dissertation has focused on adults (individuals 18 years and older) with HPD, and therefore findings from childhood and adolescent literature fall outside the scope of the discussion.

Executive Functioning

Suchy (2009) defines executive functioning as follows:

“A multifaceted neuropsychological construct that can be defined as forming, maintaining and shifting mental sets, corresponding to the abilities to reason and generate goals and plans, maintain focus and motivation to follow through with goals and plans, and flexibly alter goals and plans in response to changing contingencies.”

With the above definition in mind, it is clear that executive functioning is a significant modality which impacts everyday functioning in key ways. In our review of the literature, we looked at many cognitive modalities which will be discussed in the following section.

Working Memory

WM is one of the major components of executive functioning and can be defined as the ability to hold information in mind and manipulate it during a short time period (Diamond, 2013; Klingberg, Forssberg, & Westerberg, 2002). Studies have indicated that patients with HPD experience impairment in WM (Chamberlain, Fineberg, et al., 2007; Slikboer et al., 2018; Stanley, Hannay, & Breckenridge, 1997). While strategy ability was intact, patients with HPD presented with more between-errors at increased levels of difficulty in a spatial WM task, compared to healthy controls (HC) (Chamberlain, Fineberg, et al., 2007). Performance on various divided attention measurements (i.e. Trail Making B, Paced Auditory Serial Addition Test, Stroop, WAIS-R Arithmetic subscale) was significantly lower in the HPD group compared to matched HC (Stanley, Hannay, et al., 1997), a finding that has been replicated in subsequent work (Bohne, Keuthen, et al., 2005; Bohne et al., 2008; Keuthen, Savage, O'Sullivan, et al., 1996). WM and inhibitory control are linked and interdependent, as keeping a goal in mind is essential in knowing what to inhibit, and inhibiting internal and external influences are essential in being able to effectively focus on WM (Diamond, 2013). Impulse control (IC) is discussed in the next section.

Impulse Control

Impulse or inhibitory control can be defined as the ability to take more appropriate action through control of cognitions, behaviour, attention and emotions, even in the presence of an internal urge or external stimuli (Diamond, 2013). Multiple studies provided evidence that HPD is characterized by IC difficulty (Chamberlain, Blackwell, Fineberg, Robbins, & Sahakian, 2006; Chamberlain, Fineberg, Blackwell, Robbins, & Sahakian, 2006; Stein, Simeon, Cohen, & Hollander, 1995; Stein et al., 2010; Wetterneck, Lee, Flessner, Leonard, & Woods, 2016). Neurocognitive models identify HPD as a habit disorder in which patients find it difficult to practice adequate top-down inhibitory control, which is key to executive functioning (Chamberlain, Blackwell, Fineberg, Robbins, & Sahakian, 2005; Chamberlain, Menzies, Sahakian, & Fineberg, 2007). HPD patients presented with significantly impaired performance compared to controls in response inhibition (Odlaug, Chamberlain, Derbyshire, Leppink, & Grant, 2014a). Roberts et al. (2014) showed patients with HPD had decreased levels of response monitoring, as they have smaller error-related negativity. Participants' own perceived control over hair-pulling, were also impaired in comparison to controls (Keuthen, Savage, O'Sullivan, et al., 1996).

HPD patients find it challenging to control the motor response of pulling hair (Stanley, Hannay, et al., 1997), as well as cancelling an action when already busy. The inability to cancel the action appears to correlate with symptoms severity (Chamberlain, Fineberg, et al., 2006), whereas restraining the action was shown to be particularly impaired in patients with early onset HPD (Bohne, Savage, Deckersbach, Keuthen, & Wilhelm, 2008). When compared with HCs, patients with later-onset HPD were characterized by more impaired stop-signal reactions. In contrast, childhood onset HPD showed set-shifting difficulties but fair stop-signal performance (Odlaug, Chamberlain, Harvanko, & Grant, 2012).

A review focusing on response inhibition and interference control in obsessive-compulsive spectrum disorders highlighted inhibition impairment in HPD (Van Velzen, Vriend, De Wit, &

Van den Heuvel, 2014). Impaired ability in response flexibility was indicated which could be translated to difficulty in stopping hair-pulling once started (Bohne, Savage, et al., 2005). In a study where response impulsivity (as measured by the Stop-Signal task) and cognitive flexibility (as measured by the Set Shift Task) were measured in pathological skin-picking (PSP) and HPD compared to matched controls, the HPD group did not differ significantly from the control or the PSP group with regards to inhibitory deficits/response impulsivity and maintained an intermediate position between the two (Grant, Odlaug, & Chamberlain, 2011).

Defective response inhibition links to impairments in other cognitive functions such as ER, self-regulation or IC. A study of body-focused repetitive behaviours (BFRBs), compared to HC, found that patients with BFRBs struggled with emotional clarity, found it difficult to control impulses and access strategies to regulate emotions, as well as finding it difficult to 'snap out' of the emotions (Roberts, O'Connor, Aardema, Bélanger, & Courchesne, 2016). In the next section emotional regulation (ER) is discussed.

Emotional Regulation

Eisenberg and Spinrad (2004) reviewed various definitions of ER and described their understanding as follows:

“the process of initiating, avoiding, inhibiting, maintaining, or modulating the occurrence, form, intensity, or duration of internal feeling states, emotion-related physiological, attentional processes, motivational states, and / or the behavioral concomitants of emotion in the service of accomplishing affect-related biological or social adaptation or achieving individual goals.”

Taking the above definition into consideration, it is clear how difficulty in IC, can impact on ER. BFRBs, including hair-pulling, might be triggered by boredom, frustration, impatience and dissatisfaction (Roberts, Stanley, Franklin, & Simons, 2014) and that pulling may aid in

decreasing challenging emotions (Stanley, Borden, Mouton, & Breckenridge, 1995). People with high focused hair-pulling behaviour presented with more intense emotions and regulated their emotions more by pulling than the other subtypes (Curley, Tung, & Keuthen, 2016; Siwiec & McBride, 2016). HPD patients find it more challenging to control their anger and have higher rates of anger turned inwards, which was also correlated with hair-pulling severity (HPS) (Curley, Tung, & Keuthen, 2016). When controlling for depression, HPD participants showed significantly more difficulty regulating emotions, tolerating distress and higher levels of experiential avoidance than the non-symptomatic group (Arabatzoudis, Rehm, Nedeljkovic, & Moulding, 2017). People with HPD pay more attention to negative stimuli than what would generally be expected (Bohne, Keuthen, et al., 2005). White et al., (2013) found that reward processing in HPD patients is impaired. A correlation was found between negative affect and divided attention in HPD (Stanley et al., 1997). Lee et al. (2012) showed that patients with HPD disengage from difficult emotions, causing the attention to capture and store memories, to be lacking.

Other Neurocognitive Challenges

The importance of reflecting on other possible neurocognitive challenges is vital for various reasons. Firstly, it gives the reader a general overview of the neurocognitive picture of an average participant with HPD and understanding the aetiology, so the treatment can be specifically targeted. Secondly, knowing which other areas might be problematic, provides information as to what else may be influencing performance in the chosen intervention. Lastly, if the challenges mentioned below are linked to highlighted challenges that will be the focus of the intervention, other modalities may also benefit from training.

Attention and Concentration

Attention does not appear to be a primary concern in patients with HPD. However, patients with HPD focus their attention disproportionately on negative information in block cued

directed forgetting task, but in contrast to OCD do not show cognitive inhibition deficits (Bohne, Keuthen, et al., 2005). When confronted with images related to hair or threat, patients with HPD presented with attentional avoidance, which was linked to severity of hair-pulling symptoms (Lee, Franklin, Turkel, Goetz, & Woods, 2012).

Motor Functioning

Studies investigating motor functioning have suggested that this is intact in HPD generally (Stanley, Hannay, et al., 1997; Stein et al., 1994), although not all data are consistent (Grant, Odlaug, & Chamberlain, 2011). Motor inhibition does not seem to be problematic in HPD (Bohne et al., 2008), even when assessment of an emotional component is added to the study (Chamberlain et al., 2007). When a behaviour is already being performed, patients with HPD appear to have difficulty inhibiting their automatic motor reactions (Samuel R Chamberlain, Fineberg, et al., 2006; Odlaug, Chamberlain, Derbyshire, Leppink, & Grant, 2014b), which might link more to IC than motor ability. With regards to motoric reaction time, there is no impairment in HPD (Chamberlain, Hampshire, et al., 2010; Grant, Odlaug, Schreiber, & Kim, 2014).

Language and Verbal Abilities

No deficits in general measures of verbal ability (Bohne, Savage, et al., 2005; Bohne, Keuthen, et al., 2005; Bohne et al., 2008; Coetzer & Stein, 1999; Stanley, Hannay, et al., 1997; Stein et al., 1997) or language (Stanley, Hannay, et al., 1997) were observed in HPD.

Memory

Short-term verbal memory seems to be intact in individuals with HPD (Bohne, Savage, et al., 2005; Bohne, Keuthen, et al., 2005; Bohne et al., 2008; Keuthen, Savage, O'sullivan, et al., 1996; Stanley, Hannay, et al., 1997). Specifically, no significant differences were noted in implicit learning between HPD patients and HC (Rauch et al., 2007). Implicit learning refers

to learning without awareness (Frensch & R nger, 2003). Free recall or recognition of words, verbal or immediate memory and visual pattern recognition memory did not show any generalized deficits in the HPD population (Bohne, Savage, et al., 2005). Various studies presented no significant impairment in visual memory (Bohne, Savage, et al., 2005; Chamberlain, Hampshire, et al., 2010; Coetzer & Stein, 1999; Stanley, Hannay, et al., 1997; Stein, Coetzer, Lee, Davids, & Bouwer, 1997). Non-verbal spatial memory, however, may be compromised in individuals with HPD (Keuthen, Savage, O'Sullivan, et al., 1996; Rettew et al., 1991).

Visual-spatial Ability / Processing

With regards to visual-spatial abilities, patients with HPD do not show any generalized deficits (Bohne, Savage, et al., 2005; Stanley, Hannay, et al., 1997). On the Stylus Maze, HPD patients presented with more errors than HC, suggesting problems with spatial processing. An association was also highlighted between HPS and performance on the maze (Rettew et al., 1991). Looking specifically at visual perception, no challenges were noted (Chamberlain, Grant, Costa, M ller, & Sahakian, 2010; Coetzer & Stein, 1999; Keuthen, Savage, O'Sullivan, et al., 1996; Rettew et al., 1991; Stanley, Hannay, et al., 1997; Stein et al., 1994). Visual-spatial ability (Coetzer & Stein, 1999; Stein et al., 1997), spatial orientation, visual search ability (Stanley, Hannay, et al., 1997), and visual-spatial rotation (Keuthen, Savage, O'Sullivan, et al., 1996; Rettew et al., 1991) seems to be intact. Visual processing speed (Chamberlain, Grant, et al., 2010), perceiving missing visual information (Coetzer & Stein, 1999; Stanley, Hannay, et al., 1997; Stein et al., 1997) and visual-spatial function when drawing a cube were not impaired (Stein et al., 1994).

Ways of Targeting These Neurocognitive Challenges

From the previous section, it can be concluded that executive functioning (i.e. WM, IC and ER) may be impaired in HPD. The next section builds the case for an innovative treatment addressing the above challenges, as the focus of an intervention.

Cognitive Training

Cognitive training (CT) is a novel intervention that targets neural networks with the aim of transforming the functional patterns in the brain (Subramaniam & Vinogradov, 2013; Vinogradov, Fisher, & De Villers-Sidani, 2012). The neural prefrontal pathways indicated in neuropsychiatric illness have a high degree of learning-dependent plasticity (Vinogradov et al., 2012), and the positive impact of CT on neuroplasticity in these indicated pathways have recently been emphasized in independent studies in various conditions (Brooks, 2014; Brooks et al., 2016; Miró-Padilla et al., 2018; París et al., 2011; Peckham & Johnson, 2018; Perez-Martin, Gonzalez-Platas, Eguia-Del Rio, Croissier-Elias, & Sosa, 2017; Rizkalla, 2015).

CT may be of benefit for several reasons, e.g. it focuses on specific neurocognitive deficits, it can be administered using computers or smart phones, whilst also easy to integrate into a daily routine. An essential benefit of CT is that it makes treatment more accessible whilst providing the opportunity for tracking compliance and progress more effectively online (Brooks, 2014; Corbett et al., 2015).

There are many publicly available versions of CT. In selecting the appropriate CT intervention, consideration of the characteristics of a potentially successful CT program is key. Individual limitations in perceptual and pre-attentive processing should be addressed, and the training must be intensive and done under controlled circumstances, whilst utilizing implicit learning mechanisms (Vinogradov et al., 2012). Reward motivation is important for the mechanism of successful learning (Adcock, Thangavel, Whitfield-Gabrieli, Knutson, &

Gabrieli, 2006), and therefore it is vital that the tasks are challenging, but not too difficult (Ryan & Deci, 2000). Consideration needs to be given to individual differences participants may experience at baseline – like being uninterested or expressing frustration when the task becomes too challenging (Jaeggi, Buschkuhl, Jonides, & Shah, 2011). Increased improvement may be seen when the training is individualized (Peretz et al., 2011). Improved abilities after training are mainly linked to a specific task (Haut, Lim, & MacDonald, 2010), suggesting that the task needs to be very specifically linked to the desired outcome.

Computerized Cognitive Training

Computerized cognitive training (CCT) has been proven of value in psychiatric disorders such as ADHD (Klingberg, 2010; Klingberg et al., 2005, 2002) and schizophrenia (Twamley, Savla, Zurhellen, Heaton, & Jeste, 2008) in improving various cognitive modalities, including executive functioning, quality of life and functional capacity, as well as attention and WM network activation, linking to the dorsolateral prefrontal cortex, frontopolar cortex and anterior cingulate (Haut et al., 2010). Various studies have shown the benefit of WM training in schizophrenia, showing improvement in cognitive deficits (Fisher, Holland, Michael Merzenich, & Vinogradov, 2009); in addictions, showing lower cravings (Bickel, Yi, Landes, Hill, & Baxter, 2011), as well as improving IC in adolescents with an alcohol dependence risk (Weiland et al., 2012). Klingberg (2016) hypothesises that WM training might rely on the same processes as normal WM development based on structural maturation, interactive specialization and skill learning that look similar for development as for training. Increased connectivity during rest has been shown after WM training, and more specifically WM training led to increased functional activity, especially in the frontal and temporal lobe (Constantinidis & Klingberg, 2016; Jolles, Van Buchem, Crone, & Rombouts, 2013; Thompson, Waskom, & Gabrieli, 2016). Neural connectivity at rest and WM improvements showed strong associations after training (Aster, Barnes, Baker, Colclough, & Woolrich, 2015). More specifically, several studies have identified CT as efficacious in

enhancing executive functioning and more specifically WM in healthy individuals (Klingberg, 2010; Klingberg et al., 2005, 2002; Tulbure & Siberescu, 2013), as well as individuals with WM impairment (Klingberg et al., 2005; Mezzacappa & Buckner, 2010; Vogt et al., 2009) and psychiatric illness (Subramaniam et al., 2012; Subramaniam & Vinogradov, 2013). Group differences in WM were shown between two groups (one training group and one placebo group) even 3 months post-training (Roughan & Hadwin, 2011).

The frontoparietal network which is involved in WM, also plays a role in ER, and therefore when this network is activated by executive functioning tasks, like WM training, ER should hypothetically improve (Fagundo et al., 2013; Fernández-Aranda et al., 2012; Schweizer, Grahn, Hampshire, Mobbs, & Dalgleish, 2013). Brooks et al. (2016) suggest that WM can play a role in the gaining of clinical improvements, as well as better self-regulation skills, while also encouraging neuroplasticity. The focus of CT is on increasing the patient's capacity for better self-control, relaxation and ER, as well as positive reinforcement of these behaviours, aids in making it easier to reach goals and build self-confidence to continue (Fernández-Aranda et al., 2012). The extent to which activation occurs influences performance on attention and concentration (Haut et al., 2010). Delay discounting also improved when substance-dependent subjects received CT that is focused on WM (Bickel et al., 2011). In HPD, there has been some progress in showing benefit of online treatment modalities, albeit without a significant evidence-base yet. For example, a project that involved a 10-week online self-help program, based in HRT, suggested a clinically significant improvement of self-reported hair-pulling (Rogers et al., 2014). There was a positive correlation between the number of times a participant accessed the site and symptom improvement (Rogers et al., 2014).

In comparison with conventional computer games, personalized and self-adjusting CCT showed significant improvement in visual-spatial learning and visual WM in a healthy population, although both interventions showed benefit (Peretz et al., 2011). CCT versus a computer game control was tested in patients with schizophrenia and the CCT group

presented with significant activation of the medial prefrontal cortex, not seen in the game control (Subramaniam et al., 2012). A review article compared six computerized software packages Cogmed Working Memory Training (Cogmed), Posit Science, Attention Process Training (APT-3), Luminosity, ACTIVATE and Neuroracer) showing promise concerning their empirical findings on neuroplasticity (Brooks, 2014). Another computerized treatment program, PlayMancer/Islands, has shown clinical effectiveness in the treatment of bulimia nervosa, specifically speaking to difficulties these patients experience in ER and impulsivity, and showed success in reducing impulsivity and increasing ER (Fagundo et al., 2013). Currently many reviews are looking at the effectiveness, appropriateness and feasibility of different modalities of cognitive training, on its own as well as augmenting other treatment types (Ballesteros, Voelcker-Rehage, & Bherer, 2018; Bell, Laws, Pittman, & Johannesen, 2018; Webb, Loh, Lampit, Bateman, & Birney, 2018)

CCT appears to be an appropriate vehicle for the delivery of treatment as a cost-effective and accessible modality which has shown efficacy in various psychiatric disorders.

Brief Chapter Overview

This chapter highlighted the deficits characteristic of HPD as WM, IC and ER difficulties, all components of executive functioning, as additional targets for treatment. It also reviewed interventions that may be able to address these deficits. CT has shown efficacy in targeting WM, IC, ER, cognitive appraisal, motivated behaviour, social cognition and self-referential processing (Vinogradov et al., 2012). CT, which may be computer- and home-based, may be particularly useful in resource-constrained environments, where access to well-trained mental health clinicians is not available, to possibly overcome the above challenges (including that of distance/costs) in the treatment of HPD.

The next chapter, Chapter 3 provides an overview of the aims and hypotheses the research study wishes to answer.

“I had a positive experience. I think it is definitely a good thing, because like I didn’t think people really understand or realize that something like this seems so minor but it’s so debilitating. It’s definitely something that you know, that the people who suffer from it h’m, it’s t’s major to us. So, you know to do a study like this is to find out why, what the reasons are and what the links are and how to improve it. It’s I think it is definitely a good thing.”

Research Participant

Chapter 3: Aims and Hypotheses

Introduction

The previous chapter provided a summary of the neurocognitive challenges faced by people with HPD and an intervention that might show appropriateness and feasibility in addressing these difficulties. The following chapter provides an overview of the aims and hypotheses of the research study embarked upon, in an attempt to find an acceptable and feasible alternative to existing interventions.

Aims and Hypotheses

Three aims were highlighted in the study, to establish the impact of CWMT on HPS, WM, IC and ER in participants with primary HPD, compared to a control condition. Study findings also provided information on whether an internet-based CWMT intervention, done at participants' homes, with virtual regular monitoring by a clinician, was feasible as a mode of treatment for HPD in SA.

The next section covers the 3 aims and the hypotheses of the study.

Research Aim 1

The first aim was to determine the effect of CWMT (25 sessions over 5 weeks) on HPS in participants with HPD immediately post-intervention, at 3 months post-intervention, and whether there was a significant difference in effect on HPS between a cognitive training group (CTG) and an active control group (PG) at the various contact times. The primary outcome measure was highlighted as HPS at 5-weeks as measured by the Massachusetts General Hospital - Hair-pulling Scale (MGH-HPS).

It was hypothesised that after 5 weeks of CWMT, there would be a significant reduction in HPS and that this treatment effect would be maintained at 3 months post-intervention. The PG would not show any of these effects, at any of the time points.

Research Aim 2

The second aim was to determine the effect of CWMT (25 sessions over 5 weeks) on WM, IC and ER in participants with HPD immediately post-intervention, determine whether treatment effects were maintained at 3 months post-intervention and whether there was a significant difference in effect on WM, IC and ER in CTG and PG at the various contact times.

It was hypothesised that after 5 weeks of CWMT, there would be a significant improvement in WM, IC and ER and this treatment effect would be maintained at 3 months post-intervention. The PG would not show any of these effects, at any of the time points.

Research Aim 3

The third aim was to qualitatively explore participants' subjective experience of living with HPD, as well as their experience of the intervention process and responses to CWMT. The experience of living with HPD was assessed in all research participants who completed the first contact, while experience of the intervention was assessed in all members of both the CTG and PG.

Research interview questions were asked at each contact session and are described in more detail in Chapter 4: Methodology.

Brief Chapter Overview

The short chapter highlighted the three research aims and their hypotheses that formed the baseline of the study. The next chapter, Chapter 4, will focus on the CWMT intervention as

the researched treatment of choice, while providing an outline and description of the methodology utilized.

“I came across an article, I think in my teens in a magazine that related to hair pulling or something or the other. I think that is when I had a light bulb moment. I thought you know I have a problem, there is nothing wrong with me - I have a problem and there is such a problem.”

Research Participant

Chapter 4: Methodology

Introduction

The following chapter provides an overview of the research design, participant population, the cognitive training and control condition, research methods, data collection and data analysis. Cogmed Working Memory Training (Cogmed) (Ralph, 2014) was selected as the treatment of choice, firstly due to its efficacy in improving cognitive control, and secondly, because the training concentrates specifically on WM as the sole focus of the intervention.

Research Design

The study design was a single-blind, randomized 5-week, 25-session intervention study with control condition, immediate post-intervention, as well as a 3-month follow-up evaluation. As a registered clinical psychologist, the PhD candidate had the expertise to diagnose, do clinical interviews, and implement the psychometric battery pre- and post-intervention. She completed the Researcher Coach Training of Cogmed (Ralph, 2014), and provided support to participants during the training.

Participant Population

Professor Christine Lochner (MRC Unit on Anxiety and Stress Disorders, Department of Psychiatry, Stellenbosch University) assisted with recruitment and screening of potential participants. Participants were recruited via website advertisements (The Mental Health Information Centre of Southern Africa - blogs.sun.ac.za/mhic, Department of Psychiatry (SU) and MRC web pages), social media advertisements (e.g. health24.com, Facebook), as well as informative talks and articles on HPD, linked to other media sources (radio, local newspapers, information leaflets). Researchers also informed local mental health clinicians of the trial, encouraging referral of suitable participants. *The sampling method was thus non-*

probability purposive sampling which fit both into the quantitative and qualitative data gathering frameworks.

Inclusion Criteria

The inclusion criteria of participants consisted of the following:

- A primary diagnosis of HPD (DSM-5);
- Adults (18 years and older);
- Fluent in English;
- Access to the internet, via a computer for the duration of their study participation;
- Not be on psychotropic medication for at least 6 weeks before the start of the study (however, eligible if on a single psychotropic medication, taken at a steady dose for at least 8 weeks and effect be stabilized as confirmed by a psychiatrist);
- Not be undergoing psychotherapy (however eligible if is in the process before the start of screening and continues for the time of trial).

Exclusion Criteria

The exclusion criteria of participants consisted of the following:

- Any significant current DSM comorbidity (major depression, obsessive-compulsive disorder, substance use disorder);
- Montgomery-Asberg Depression Rating Scale (MADRS) Score > 20 to exclude participants with comorbid major depression;
- Previous exposure to Cogmed (previous 'brain training' games on a cell phone and/or computer allowed);

Individuals who are fluent in English were included for several reasons. Firstly, most South Africans are able to speak and understand English as this is a compulsory subject in schools (De Wet & Wolhuter, 2009). Secondly, the trial entailed a training program that is available in

English (A. Winter, personal communication, January 10, 2016). Lastly, the researcher and her supervisors are fluent in English, facilitating communication.

Participants should not be on psychotropic medication for at least six weeks before starting the trial, but participants remained eligible if they were receiving treatment with a psychotropic medication at the time of screening, provided the following restrictions were met: 1. They were only receiving treatment with a single psychotropic medication. 2. The medication that they were being treated with, have been taken at a steady dose, for at least 2 months (8 weeks), and the effect stabilized according to the treating psychiatrist. Also, participants should also preferably not have been undergoing psychotherapy, but remained eligible if they were receiving treatment from a psychologist or other mental health clinician at the time of screening and continues to do so for the duration of the trial.

Subjects were screened for chronic medical conditions, including detailed history taking of brain injuries, serious medical illnesses such as dermatological infections, meningitis, encephalitis, or brain tumours, and developmental delays. Participants were only excluded where their medical condition impacted on their ability to do the intervention.

Before the initial screening session at Stikland Hospital, conducted by the PhD candidate, or at Tygerberg Hospital, conducted by Prof Lochner, the study Patient Informed Consent Form (PICF) was discussed with the participant in English or Afrikaans, depending on their preference. Any questions that arose from the discussion were answered to make sure that the participant had a good grasp on what the study entailed, what was expected of him/her and what can be expected of the researcher. Thereafter two duplicate documents were signed – for both the participant and researcher's records. During the initial telephonic screening, the inclusion and exclusion criteria were discussed and checked with the prospective participant. Once established that the interested individual was suitable for participation, he/she was invited to a comprehensive screening interview at either Stikland or Tygerberg Hospital. The criteria for HPD according to the DSM-5 was checked to verify the

current diagnosis of HPD. The MGH-HPS was used as primary outcome measure to assess HPS.

Diagnostic interviews included the Structured Clinical Interview for Axis I Disorders-Patient Version (SCID-I/P) (First, Spitzer, Gibbon, & Williams, 1998), the Expanded Structured Clinical Interview for DSM-5 for Obsessive-Compulsive Spectrum Disorders (SCID-OCSD-11) (Lochner, Du Toit, Breet, Van Kradenburg, & Stein, 2014) and the Montgomery Asberg Depression Rating Scale (MADRS) (Montgomery & Asberg, 1979).

Randomization

Participants recruited to the study were randomly assigned to the cognitive training group (CTG) or the active control group (PG), using a randomization list provided by the statistician. The CWMT, Cogmed (Cogmed QM) and the control condition (The Jigsaw Puzzles) differ significantly. The PhD candidate was not blind to the group that the participants were in, whereas the participants were blind to their group inclusion. Matching the extent and type of contact (besides the type of intervention, of course) that the PhD candidate had with participants in both groups, ensured fidelity and compliance in the PG as well.

Sample Characteristics

A sample size of 30 (16 CTG, 14 PG) was achieved. Initially, it was aimed to include 20 participants in each group, as this was comparable to group sizes in other HPD treatment studies. Literature on CT in HPD is non-existent, it was therefore not possible to provide a power calculation for the effects of CT on HPD symptoms. Based on previous publications in the field of WM and OCD (i.e. a disorder sharing phenomenological and psychobiological features with HPD) (Abramovitch, Abramowitz, & Mittelman, 2013; De Vries et al., 2014), as well as other intervention studies that investigated HPD (Falkenstein, Rogers, Malloy, & Haaga, 2015; Grant et al., 2014; Keuthen et al., 2012; McGuire et al., 2014; Rehm et al.,

2015) and the use of WM training (Bickel et al., 2011; S. J. Brooks et al., 2016; Etherton, Oberle, Rhoton, & Ney, 2018; Jolles et al., 2013; Roughan & Hadwin, 2011; Vogt et al., 2009) an average around 20 participants in each group to adequately demonstrate a statistically significant difference in scores should have been sufficient. On completion of the study, if Cogmed showed benefit compared to control, participants who were included in the control arm, would gain access to the intervention, should they wish to complete the Cogmed QM program.

By the end of recruitment, a total of 30 participants were included. We were then able to run a power analysis (using the primary outcome data – MGH-HPS) which suggested that for an effect size of 80%, 35 participants in each group would have been ideal. In the current study, with 30 participants, the power analysis provided an indication of power of 0.44 (medium effect size).

Study Intervention

Cognitive Working Memory Training: Cogmed

Cogmed software (Pearson, 2016; Ralph, 2014), (which showed efficacy in improving WM, attention, cognitive functioning in daily life, attentional problems in ADHD and cognitive control, as well as reduction of symptoms in adults with acquired brain injury) was the identified intervention for the research study. Cogmed is an internet-based training program that adheres to these above-mentioned recommendations. It focuses on spatial and auditory WM tasks, which increases in difficulty over sessions. The user starts at the basic level, with his/her baseline after initial assessment and progresses at his/her own pace as the training continues (Ralph, 2014). Cogmed QM was developed for adults and comprises of eleven verbal and visual-spatial tasks, which adjust in difficulty each day. Depending on the protocol chosen, two to eight tasks (Figure 1,

Figure 2) can be completed per daily session, which may be either 25, 35 or 50 minutes and training lasts for five to 10 weeks (Ralph, 2014). Figure 1 shows the various working memory tasks that may be part of the daily training. Figure 2 is an example of the task 'Hidden', where participants have to recall the correct sequence in which the blocks lit up.

Figure 1: Cogmed - Various tasks

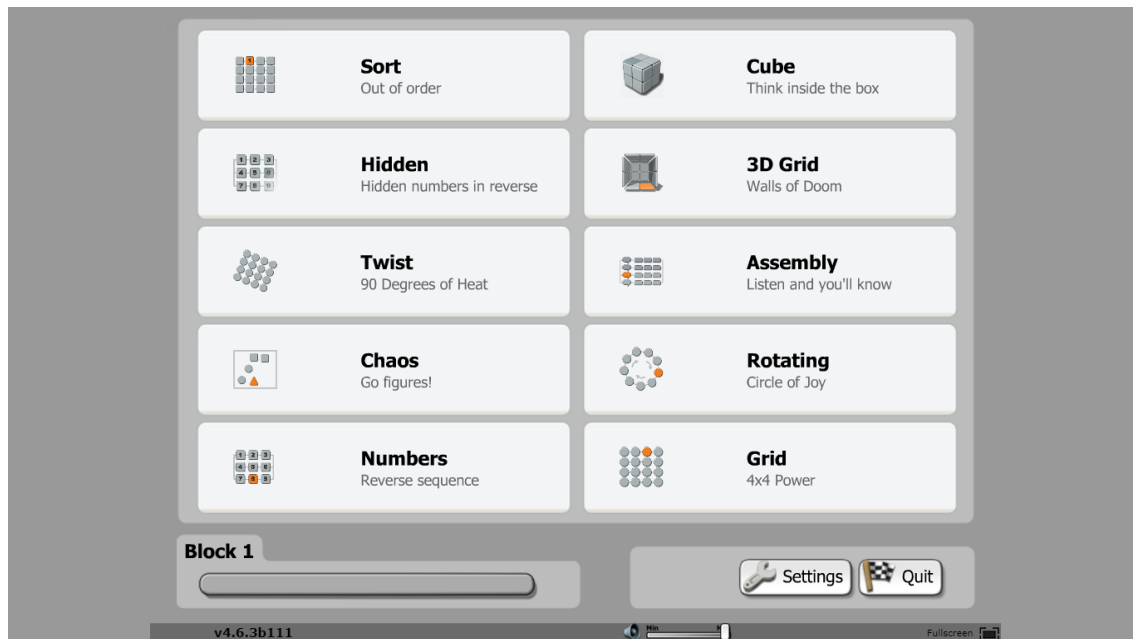
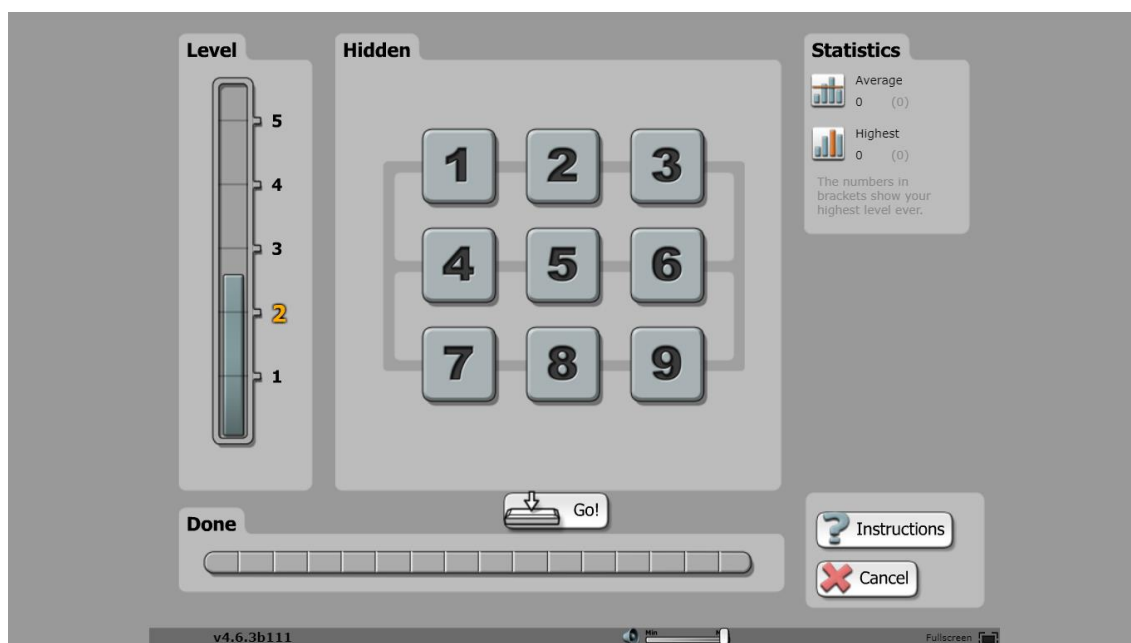


Figure 2: 'Hidden' task screen print

For the purposes of this study, the standard protocol for Cogmed was used, which included 50-minute sessions, five days per week, for five weeks. A compliance cut-off of 80% is recommended, which implicates that 20 sessions of the standard protocol must be completed. The Cogmed coach, in this case the PhD candidate, provided support to ensure fidelity and compliance to the program. Seeing as training WM was the sole focus of the needed intervention, Cogmed was an evidence-based tried and tested choice. Project funding made it possible to gain access to this 'true WM' training, cutting out training in other modalities that may influence the findings.

This mode does not come without its own challenges though. Firstly, it would be important to see whether it was Cogmed or cognitive training in general that made the difference to pulling. Secondly, Cogmed is expensive, so if it shows benefit, it would be a need to find alternatives that are cheaper, and thirdly, Cogmed is only available through a Cogmed Qualified Practice and a Cogmed Coach need to support the patient throughout the training through weekly telephonic or online check-ins.

Control Condition: The Jigsaw Puzzles

The control condition, 'The Jigsaw Puzzles' (Figure 3) provided an experience of working on a computer for the same amount of time that the CTG members were working on their tasks. The participant did the puzzle of the day firstly and thereafter could choose a puzzle of their choice from the puzzle gallery. The difficulty level remained the same to minimize any training. The participants sent the time spent on each puzzle after completion via automated e-mail, which was how the PhD candidate monitored the PG compliance.

Figure 3: The Jigsaw Puzzle example



Research Method

In the next section, the method of research is discussed, with specific reference to both the qualitative and quantitative aspects of the project. It is relatively uncommon for RCTs to include qualitative data, despite the contribution that these can make to understanding the impact of interventions.

The research method was based on concurrent embedded theory design (Creswell, 2009), utilizing both quantitative and qualitative components which were collected simultaneously.

The quantitative data encompasses the bulk of the information gathered and focused on the hypotheses linked to the treatment intervention outcomes only, whereas the qualitative data answered questions regarding the experience of the training as well as the experience of living with HPD. The benefit of this mixed-methods approach was to be able to investigate and describe subject matter with statistical power, as well as being able to comment on the participants' experience, thus creating a richer and more holistic description of the research theme. Berk et al. (2011) hypothesized that a more comprehensive data set might be collected when qualitative components are also included in the process, which complements the quantitative information gathered and can lead to more inclusive monitoring of the acceptability and feasibility concerning the researched topic.

Quantitative Research

The quantitative research consisted of the pre- and post-intervention assessment battery, 3-month follow-up evaluation and continuous information provided by the treatment intervention. Questionnaires were completed with the assistance of the researchers as needed, whether self-report or clinician driven, and was available in English. Quantitative measures for the study included a demographic questionnaire, as well as scales focusing on HPS, general functioning, IC, ER and a brief general intellectual assessment and WM tasks. The option of including before and after photos during the assessment sessions was considered. However, the photos might be viewed as an intervention and could lead to an increased response to the control condition. There was also uncertainty about how to rate these photos objectively. Therefore, it was decided to rather focus on data gathered using objective (clinician's impressions) and subjective (participant's self-report) measures.

Qualitative Research

As previously mentioned, the subjective experience of participants can assist in the development of more appropriate interventions that can speak to the need of the patient with

HPD and increase compliance to treatment. The focus was on the participants' experience of living with HPD, as well as their experience of the treatment intervention and effects thereof on HPD symptoms and general functioning. The researcher was in an excellent position to conduct these interviews, given her experience in clinical practice.

An interpretative phenomenological approach was used in the qualitative data analysis of the semi-structured interviews, including open-ended questions used as part of the pre- and post-assessment battery and 3-month follow-up evaluation. The PhD candidate is well-versed in both English and Afrikaans, and thus interviews were conducted in either language, whichever the participant felt more comfortable with. The length of interviews ranged from 5 to 20 minutes, depending on the participant's willingness to engage. These interviews were audiotaped and transcribed. Transcriptions were not translated before analyzed, because of the risk of the meaning of language and nuances being misinterpreted. In gaining more understanding of the participant's experience, translating after coding should maintain the reliability and validity of the data more effectively (Twinn, 1997). (For the purpose of the English reader being able to understand, the Afrikaans quotations added in the text have been translated to English).

Research Instruments

The assessment battery consisted of a range of instruments, from assessing appropriateness to the study concerning in- and exclusion criteria, including an indication of general intellectual functioning, as well as gaining more information on hair-pulling behaviour, WM, IC and ER.

In the following sections, the research instruments utilized during data collection will be discussed.

Sociodemographic Questionnaire

This questionnaire included information on gender, age, population, language, marital status, the highest level of education, number of years of education, occupation, access to internet and contact details of other treating clinicians.

Screening Assessments

The Montgomery Asberg Depression Rating Scale (MADRS) is a short, 10-item questionnaire, scored after an interview with the patient, with a minimum and maximum score of 0 and 60 respectively. Each item is scored between 0 and 6 and speaks to the core symptoms of depression. Higher scores are more indicative of depression. The MADRS shows good inter-rater reliability and validity in monitoring depressive symptoms (Montgomery & Asberg, 1979). It is also sensitive in distinguishing depressed patients from non-depressed patients with cognitive impairments (Knapskog, Barca, & Engedal, 2011). Participants were excluded from the study if they scored 20 or more on the MADRS.

The Structured Clinical Interview for Axis I Disorders-Patient Version (SCID-I/P) (First et al., 1998) was used to screen participants for another comorbid diagnosis which may contribute to their exclusion from the study (e.g. mood and anxiety disorders, substance abuse etc.). This version of the SCID is designed for participants who are part of a psychiatric population (First et al., 1998).

The Expanded Structured Clinical Interview for DSM-5 for Obsessive-Compulsive Spectrum Disorders (SCID-OCSD-11) was developed using the format of the original SCID-I/P (mentioned above) and is a structured clinician-administered instrument that specifically assesses for symptoms of the obsessive-compulsive spectrum disorders (Lochner et al., 2014).

The Wechsler Abbreviated Scale of Intelligence – Full Scale-2 (WASI Full Scale-2) was introduced in 1999 and is a test that is individually administered to testees between the ages of 6 and 89 years (Wechsler, 1999). The WASI Full Scale-4 is comprised of

Vocabulary, Block Design, Similarities and Matrix Reasoning as the four subtests, but in the WASI Full Scale-2, only the Vocabulary and Matrix Reasoning subtests are utilized. The two-subtest form takes 15 minutes to complete and provides a general estimation of intellectual ability, the FSIQ score. The instrument has shown significant test-retest and inter-rater reliability (Wechsler, 1999).

Hair-pulling Symptoms

The primary outcome measure for the hair-pulling symptoms was the Massachusetts General Hospital Hair-Pulling Scale (MGH-HPS) (Keuthen et al., 1995). This self-report scale is widely used and often in studies wanting to document changes in hair-pulling over time. It focuses on the severity of the hair-pulling and resistance/control of the urges in the past week. Higher scores indicate greater symptom severity and are scored on a 7 item 5-point Likert scale, totalling between a score between 0 and 28 (Diefenbach, Tolin, Crocetto, Maltby, & Hannan, 2005; Keuthen et al., 1995; O'Sullivan et al., 1995).

The Clinical Global Impression scale is a clinician-rated scale that has shown validity and reliability, and objectively measures symptom severity (CGI-S) using a Likert-scored scale with 1= 'not ill at all' to 7= 'among the most extremely ill' (Guy, 1976). The other CGI component gives an impression of improvement or worsening of symptoms (CGI-I), which is scored on a Likert scale with 1= 'Very much improved' to 7= 'very much worse'. The CGI-S was completed at baseline and the CGI-I during the two follow-up sessions.

On the assessment of psychosocial functioning in areas of life – work, social, as well as home and family life - another valid and reliable 3-item self-report discretized analog scale was used, namely the Sheehan Disability Scale (SDS). It has a score range of 0 – 30 and has shown good sensitivity to treatment effects (Sheehan & Sheehan, 2008).

Working Memory

The Letter-Number Sequencing (LNS) and Digit Span (DS) are subtests of the Wechsler Adult Intelligence Scale – 3rd edition (WAIS-III), that focus on WM. LNS asks the participant to switch between letters and numbers in organizing a list provided verbally, whereas DS consists of two subtests – repeating lists of numbers forwards and backwards. LNS is considered a more complex WM task than DS. On both these subtests, the higher the score that is obtained, the better the participant's WM is deemed to be (Wechsler, 1997).

Impulse Control

The Barratt Impulsiveness Scale (BIS-11) is a 30-item measurement which assesses the participant's impulsiveness with regards to sub-traits. It consists of 3 second-order factors, made up of 6 first-order factors – Motor Impulsiveness: Motor and Perseverance; Non-planning Impulsiveness: Self-control and Cognitive Complexity, and Attentional Impulsiveness: Attention and Cognitive Instability (Stanford et al., 2009). The higher the score, the more impulsive the person is deemed to be with regards to the given factor.

The Stroop Color and Word Test – Adult Version (SCWT-A) is an assessment that, in the presence of normal reading skill, gives an indication of an adult's ability to selectively react to stimuli in his environment. The assessment consists of three pages with 100 items each – a Color, Word and Color-Word page. The model proposes that when a word is written in a different colour than stated in the word, the average person will read the word, before naming the colour. When then asked to name the colour instead, individuals find it hard inhibit the natural response i.e. reading the word. When inhibition occurs, the Color-Word score is higher than predicted. If not, cognitive inflexibility makes it more difficult to inhibit and score lower than predicted, which provides an Interference score of positive and negative value irrespectively (Golden & Freshwater, 2002).

Emotional Regulation

The Affective Regulation Scale (ARS) focuses on the ability to control emotions that participants rate on a 5-point Likert scale – ranging from 0= “Never able to control” to 4= “Always able to control”. The emotions include bored, angry, guilty, indifferent, tense, irritable, sad, anxious and ashamed. Lower scores indicate that a participant finds it more challenging to regulate emotion. The second part of the ARS looks at whether the participant makes a link between emotions and pulling. This is rated on a 3-point Likert scale – ranging from 0= “Never causes hair-pulling” to 2= “Often causes hair-pulling”. Once again, lower scores indicate participants’ belief that there is less of a link between emotions and pulling. This assessment also showed adequate reliability (Shusterman et al., 2009).

The Difficulty in Emotional Regulation Scale (DERS) reflects on 6 areas where challenges may be experienced. These areas are lack of emotional awareness, IC difficulties, difficulties engaging in goal-directed behaviour, limited access to effective ER strategies, lack of emotional clarity and non-acceptance of emotional responses. These areas are covered in 36 questions and the assessment presents with internal consistency and test-retest validity (Gratz & Roemer, 2004). Higher scores indicate more difficulty in the specific area.

Clinical Interviews

Each contact session had different questions to open the discussion. These questions are stated below.

Contact 1: Screening and Orientation Session – The Experience of Living with Hair-pulling Disorder: *“Tell me about life with Trichotillomania?”* and *“How would life be different without Trichotillomania?”*

Contact 2: Immediate Post-Intervention Session - Experience of Training: *“Tell me about your experience of being part of the study?”* and *“Tell me about your experience with the cognitive training?”*

Contact 3: 3-month Follow-up Session - Reflection on Past 3 months and Process: *“Tell me about the 3 months since you completed the cognitive training program?”*

Data Management

Data Collection

At baseline, assessments were done at Stikland Hospital, conducted by the PhD candidate, or at Tygerberg Hospital, conducted by Prof Lochner. When the participant met all the criteria, they were randomized into the CTG or PG group. Pre- and post-intervention data collection was done by the PhD candidate by means of the assessment battery including both quantitative and qualitative measures, as previously discussed. She was present when participants completed the self-report questionnaires to ensure that questions could be answered should they arise and to check that all questions were completed. Cogmed data concerning the participants' training process was accessed online by the PhD candidate and she made weekly contact with the participants via phone or e-mail as per Cogmed protocol, to monitor compliance in training. Adherence to the control condition was also monitored by session e-mails being sent by participants via The Jigsaw Puzzles software, as well as weekly contact with the participants. In general, retention rates of 80% for adults are reported when participants train with Cogmed (K. Ralph, personal communication, May 31, 2015). The same rates were expected in this study. All digital and electronic documents containing data was saved in a password protected file and backed up on the university's system (G-drive) which was also password protected. This also included any audio-taped interviews. Data were collected from March 2016 to April 2018. By the end of December 2017, all pre-intervention data sets were complete, the end of January 2018 all immediate post-intervention data sets and the end of April 2018 all 3-month follow-up data were collected.

Data Analysis

A statistician, Professor Martin Kidd, from the Centre for Statistical Consultation, University of Stellenbosch, was consulted on the project's statistical analyses. Analyses were done using Statistica package version 13.3. Statistical analysis was conducted using mixed model repeated measures ANOVA (Littell, Milliken, Stroup, & Wolfinger, 1996; Verbeque & Molenberghs, 1997). The mixed model approach is most suitable for dealing with possible lost to follow-up. Participants in the study were treated as random effects (randomly selected from a larger population). Treatment (CWMT vs control condition) and time (pre, post, 3 months) are treated as fixed effects. The treatment*time interaction effect is the primary effect of investigation because it tests whether the change over time is the same for the two groups. If Cogmed had a different effect to the control condition, then this interaction effect should be significant. Post hoc testing was done using Fisher Least Significant Difference (LSD) testing. Normality assumptions were checked for all analyses and appropriately dealt with where necessary, based on the nature of the data. A 5% significance level was used as a guideline for significant results.

The qualitative data were analyzed using an interpretative phenomenological approach consisting of the following steps: familiarization and immersion, introducing themes, coding, elaboration, interpretation and checking (also known as saturation/exhaustion) and lastly integration of the information into a final report (Creswell, 2012; Lester, 1999; TerreBlanche, Durrheim, & Kelly, 2010). The qualitative analysis was done by means of Atlas.ti 8.1.30, a computer-assisted qualitative data analysis software program.

Ethics

The study procedures were communicated in lay terminology to all participants (verbally and in writing) in Afrikaans and/or English. Anticipated risks and benefits were disclosed to all participants. They were also informed that all data collected will be kept strictly confidential and study results made public and published without compromising confidentiality. In case of

deterioration in any of the participants, they would be withdrawn from the study and appropriate action taken. This was however not necessary. The demographics questionnaire was removed from the questionnaire pack to ensure that the completed questionnaires and the demographic details cannot be linked. Personal identifying details such as the name and contact information were not recorded on the electronic database with study data. All participants were allocated a unique study code on the electronic database. Identifiers linked to a study code were kept in a separate, password protected file. Only the PhD candidate had access to this information. It was clearly indicated that participants were free to withdraw participation from this trial, without consequence. Participating individuals incurred no costs and if requested were provided transport money to cover their travel expenses. The study protocol was submitted to and approved by the Committee for Postgraduate Teaching (CPT), the Health Research Ethics Committee (HREC) of Faculty of Health Sciences, University of Stellenbosch (US), Western Cape Department of Health and Stikland Psychiatric Hospital. The study was conducted in accordance with the guidelines of the International Conference on Harmonisation Good Clinical Practice Guidelines (International Conference on Harmonization, 2014), The Declaration of Helsinki (World Medical Association, 2013) and The Medical Research Council of South Africa's guidelines (South African Medical Research Council, 2014) on the ethical conduct of research studies in humans. The PhD candidate ensured that these guidelines were adhered to for the duration of the study and kept the HREC updated on the study progress through annual submission of project progress. The trial was also registered at clinical trials registries i.e. ClinicalTrials.gov and the Pan African Clinical Trial Registry (PACTR) with the MGH-HPS clearly marked as the primary outcome measure. Both the candidate and her supervisor are registered at the Health Professions Council of South-Africa (HPCSA) and compliant with Continuous Professional Development (CPD) guidelines.

Brief Chapter Overview

This chapter highlighted the study methodology in terms of design, measurement instruments used, and how data were analyzed. Ethical considerations were also presented. The next chapters, Chapter 5 and 6, respectively, will commence by giving feedback on the quantitative and qualitative results.

“And I know that I am, I’ve got mixed feelings, because my conscious brain says: ‘I want to give up. I must give up’. But I know that it’s a habit that I’ve learnt that plays a role in my life. And so, what will happen if I am successful in giving up the habit? Will I have something else to do? Will I transfer it to another habit or something, or uhm, or will it, I don’t know... Will it make me go mad, or will something bad happen...”

Research Participant

Chapter 5: Results - Quantitative Data

Introduction

41 participants were screened and randomized on intake to the CTG or the group receiving the control condition (PG). From here on forward, 'training' will refer to the 5 weeks all participants spent doing either CWMT or control condition, otherwise reference will be made to CTG and PG specifically.

3 participants declined participation in the study post-screening, but prior to randomization. 1 participant assigned to CTG defaulted before training started, and 1 during Week 1, 2 during Week 3 and 2 during Week 4, respectively. No CTG participants defaulted during Week 2 or 5. 1 participant assigned to the PG did not start training at all and 1 defaulted during Week 1. No other PG participants defaulted. Therefore, 11 participants did not complete the training after study inclusion and could thus not be included in the post-intervention assessments. Retention rates were expected to be 80% regarding participants who started training as previously stated (K. Ralph, personal communication, May 31, 2015). In this case, there were 6 defaulters out of 36 participants who started the training, and thus the study found an 83% retention rate.

Finally, the CTG included sixteen ($N = 16$) and the PG fourteen ($N = 14$) participants and data were collected from them at all contact times. The pre-intervention assessment will be referred to as contact time 1 (T1), the immediate post-intervention assessment as contact time 2 (T2) and the 3-month follow-up assessment as contact time 3 (T3).

The data were analysed according to statistical analysis procedures discussed in Chapter 4 (Methodology).

Sociodemographic Information

The majority of the sample was female (28 [93%]). The CTG and PG each included one male participant each. The average age of the sample was 37.8 years (± 16.6), ranging from 18 to 73 years. There was no significant difference between the intervention groups in terms of age ($F = 1.94$, $p = 0.2$) (Table 1). Supplementary sociodemographic details of participants are provided in Table 1.

Table 1 - Sociodemographic information of study participants (N = 30)

	Cognitive training group (CTG: N = 16)	Control group (PG: N = 14)	Total group (N = 30)
Gender			
Female	15	13	28 (93%)
Male	1	1	2 (7%)
Age	No significant difference (F = 1.9, p = 0.2) *		Mean: 37.8 ± 16.6
	Mean: 40.8 ± 18.1	Mean: 34.4 ± 14.6	Range: 18 – 73 years
Home language			Rao & Scott adjustment: p = 0.03
Afrikaans	21	12	6 participants indicated that their home language was both Afrikaans and English.
English	9	18	
CTG contained significantly more participants indicating Afrikaans as their home language than PG.			
Ancestry	There was no significant difference in ancestry distribution between CTG and PG. We include this classification not to reify sociocultural constructs, but in order to study ongoing health disparities in the SA context.		

White	13	11	24 (80%)
Coloured	2	1	3 (10%)
Indian	1	-	1 (3%)
Black	-	1	1 (3%)
Other	-	1	1 (3%)
Number of years of education	No significant difference ($F = 1.4$, $p = 0.3$) *		Mean: 16.2 ± 2.7
	Mean: 15.8 ± 2.0	Mean: 16.7 ± 3.2	Range: 12 – 24 years
Level of education	No significant difference (Fisher exact: $p = 0.8$) **		
	4 (25.0%)	2 (14.3%)	Matric: 6 (20%)
	3 (18.8%)	2 (14.3%)	College/Technicon: 5 (17%)
	9 (56.2%)	10 (71.4%)	University: 19 (63%)
Occupation	No significant difference (Fisher exact: $p = 0.4$) **		
	7 (43.8%)	3 (21.4%)	Professional: 20 (33.3%)
	1 (6.3%)	3 (21.4%)	Business owner: 4 (13.3%)
	2 (12.5%)	1 (7.1%)	Homemaker: 3 (10%)
	-	2 (14.3%)	Sales: 2 (6.7%)
	3 (18.8%)	3 (21.4%)	Student: 6 (20%)
	2 (12.5%)	-	Pensioner: 2 (6.7%)
	1 (6.3%)	2 (14.3)	Other: 3 (10%)
WASI Full Scale-2 (General Intellectual Ability Estimates)	No significant difference ($F = 0.02$; $p = 0.9$) *		Mean = 83.7 ± 18.3
	Mean = 83.0 ± 18.3	Mean = 84.5 ± 18.9	Suggesting above average intellectual abilities
Age of Onset of Pulling	No significant difference ($F = 0.4$; $p = 0.53$)		Mean = 14.1 ± 5.9

	Mean = 15.9 ± 5.3	Mean = 11.9 ± 5.9	
Duration of Pulling	No significant difference (F = 3.5; p = 0.07)		Mean = 23.7 ± 16.7 years
	Mean = 24.8 ± 18.9	Mean = 22.5 ± 14.4	
CTG: Cognitive training group; PG: Control group; *Levene's Test for Homogeneity of Variances; **Fisher's exact test			

Clinical Findings

The following section provides an overview of the clinical findings regarding hair-pulling symptoms, WM, IC and ER.

Hair-pulling Symptoms

Hair-pulling symptom severity was assessed using the Massachusetts General Hospital Hair-Pulling Scale (MGH-HPS), and global illness severity using the Clinical Global Impression Scale (CGI). Functional impairment due to HPD was assessed using the Sheehan Disability Scale (SDS). A detailed account of the qualities of these measuring instruments was included in Chapter 4 (Methodology).

Hair-pulling Severity

There was no significant difference between CTG and PG at T1 (mean difference = 0.3 ± 2.1, p = 0.9) indicating that both groups started their treatment at equal HPS (MGH-HPS mean = 15.4 ± 4.6, '*moderate*'). There was, however, a significant difference between CTG and PG at T2 (mean difference = 4.5 ± 2.1, p = 0.04), with CTG scoring significantly lower (mean = 8.7 ± 6.8, '*mild*') than PG (mean = 13.1 ± 5.9, '*moderate*') immediately after 5 weeks of training. However, the difference between CTG and PG at T3 was not significant at 3 months follow-up (mean difference = 3.2 ± 2.2, p = 0.1; CTG mean: 10.3 ± 5.7; PG mean: 13.2 ± 6.5, both '*moderate*') (Figure 4; Table 2).

The CTG showed a significant change between T1 and T2 (mean difference = 6.6 ± 1.7, p < 0.001), but not between T2 and T3 (mean difference = -1.6 ± 1.7, p = 0.3) - indicating that

immediately after the training period of 5 weeks, pulling severity was significantly reduced from '*moderate*' to '*mild*' and remained as such at 3 months follow-up (although the results returned to fall in the lower end of '*moderate*'). Participants in the PG showed no significant change from T1 to T2 and T3, respectively and remained in the '*moderate*' range (Figure 4; Table 2).

Figure 4: Comparison of hair-pulling severity at baseline, immediate post-intervention and 3 months' follow-up

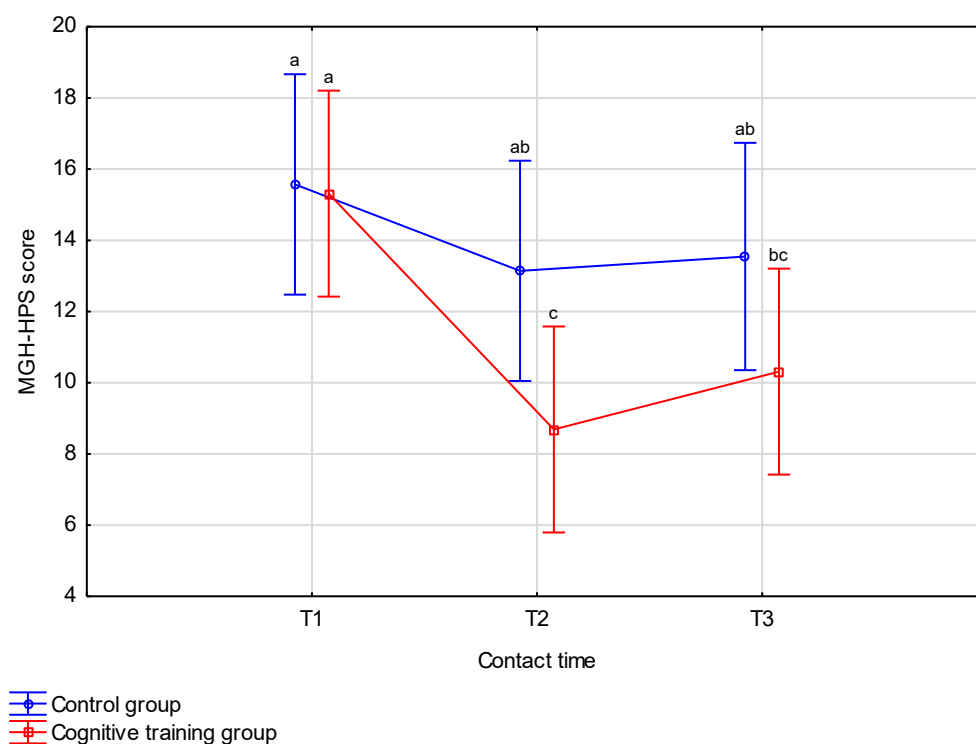


Table 2 - Comparison of hair-pulling severity at baseline, immediate post-intervention and 3 months' follow-up (MGH-HPS: Least Significant Difference Test and Descriptive Statistics)

	T1						T2						T3		
	Mean	Standard	p-value	Mean	Standard		Mean	Standard	p-value	Mean	Standard		Mean	Standard	
	Diff	Error			Deviation		Diff*	Error			Deviation		Diff**	Error	
CTG	-	-	-	15.3	4.2		6.6	1.7	<0.001	8.7	6.8		-1.6	1.7	0.3
PG	-	-	-	15.6	5.2		2.4	1.8	0.2	13.1	5.9		-0.4	1.8	0.8
CTG: PG	0.3	2.1	0.9	-	-		4.5	2.1	0.4	-	-		3.2	2.2	0.1
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data															

General Functioning

The CTG and PG did not differ significantly with regards to illness severity at T1 ($F = 0.1$; $p = 0.8$), using the CGI-S. Illness severity scores from participants in both groups ranged from 'slightly ill to moderately ill' (CGT: mean = 3.3 ± 1.4 ; PG: mean = 4.2 ± 1.4 ; total sample (CTG + PG): mean = 3.5 ± 1.1) (Table 3).

In terms of improvement in illness severity, there was no significant difference between CTG and PG at T2 (mean difference = 0.0 ± 0.5 , $p = 1.0$) using the CGI-I, which showed '*minimal improvement*' from T1 in both groups. At T3 there was also not a significant difference between the groups, but did show a trend towards significance (mean difference = 0.8 ± 0.5 , $p = 0.08$) (Figure 5; Table 3).

CTG showed no significant difference between the two contact times (mean difference = -0.3 ± 0.5 , $p = 0.5$), and showed '*minimal improvement*' in illness severity at T2 (mean = 3.0 ± 1.2) and T3 (mean = 3.3 ± 1.4) (Figure 5; Table 3). Participants in the PG presented with significant difference in scores from T2 to T3 (mean difference = -1.2 ± 0.5 , $p < 0.001$; T2 mean = 3.0 ± 1.0 , '*minimally improved*'; T3 mean = 4.2 ± 1.4 , '*no change*') (Figure 5; Table 3).

Figure 5: Comparison of clinician-rated improvement of HPD at immediate post-intervention and 3 months' follow-up

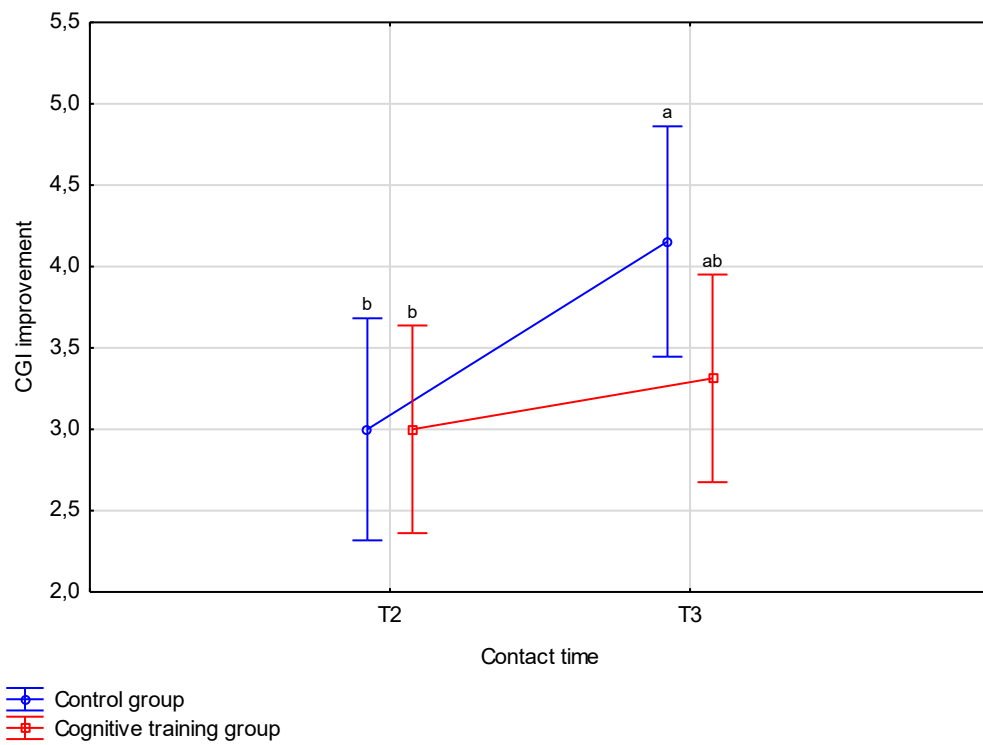


Table 3 - Comparison of clinician-rated improvement of HPD at immediate post-intervention and 3 months' follow-up (CGI: Least Significant Difference Test and Descriptive Statistics)

	T1 – CGI-S		T2 – CGI-I			T3 – CGI-I						
	Mean	Standard Error	Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
CTG	3.1	0.3	-	-	-	3.0	1.2	-0.3	0.4	0.5	3.3	1.4
PG	3.9	0.3	-	-	-	3.0	1.0	-1.2	0.5	0.02	4.2	1.4
CTG: PG	-	-	0.00	0.5	1.00	-	-	0.8	0.5	0.08	-	-
All participants	3.5	1.1	-	-	-	3.0	1.0	-	-	-	3.7	1.4

CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data

Impairment

On assessing the impact of HPD on functional impairment using the SDS, there were no significant differences between CTG and PG at T1 (mean difference = -0.9 ± 3.5 , $p = 0.8$), T2 (mean difference = -0.8 ± 3.5 , $p = 0.8$) or T3 (mean difference = -0.8 ± 3.6 , $p = 0.8$) (Figure 6; Table 4). However, the findings suggest significantly less functional impairment due to HPD in participants in CTG from T1 to T3 (mean difference = 5.6 ± 2.3 , $p = 0.02$; T1: mean = 12.0 ± 7.7 , '*moderate*'; T3: mean = 6.4 ± 10.4 , '*mild*').

Considering the SDS subscales, work impairment was deemed '*mild*' and did not significantly change in any of the two study groups (Figure 7, Table 4). However, with regards to social impairment (Figure 8) and family impairment (Figure 9), there were significant changes (Table 4) which will be considered next.

Social impairment due to HPD decreased significantly from T1 to T2 in both groups (CTG: mean difference = 1.8 ± 0.6 , $p < 0.001$; PG: mean difference = 2.6 ± 0.6 , $p < 0.001$) and remained as such at T3 (CTG: mean difference = 0.3 ± 0.6 , $p = 0.7$; PG: mean difference = -0.3 ± 0.6 , $p = 0.6$) (Figure 8, Table 4). Both decreased from the '*higher end of mild impairment*' at T1 (CTG: mean = 3.1 ± 2.2 ; PG: mean = 3.6 ± 2.8) to the '*lower end of mild impairment*' at T2 (CTG: mean = 1.3 ± 2.2 ; PG: mean = 1.0 ± 1.8) and stayed in the '*lower end of mild impairment*' at 3-month follow-up (CTG: mean = 1.1 ± 1.9 ; PG: mean = 1.2 ± 1.7). Family impairment due to HPD was significantly reduced from T1 to T2 in CTG (mean difference = 0.9 ± 0.5 , $p = 0.04$) and remained as such at 3-month follow-up (mean difference = 0.1 ± 0.5 , $p = 0.8$). Family impairment was initially reported as '*mild*' (mean = 1.9 ± 1.9) for this group, and after 5-weeks CT, was reported in the '*lower end of mild*' (mean = 0.9 ± 1.4) and remained as such on 3-month follow-up (mean = 0.8 ± 1.4). In comparison, PG remained unchanged at the '*lower end of mild*' (mean = 0.9 ± 1.5) from T1 to T2 (mean difference = -0.2 ± 0.5 , $p = 0.7$) and T3 (mean difference = -0.1 ± 0.5 , $p = 0.8$) respectively (Figure 9; Table 4).

Figure 6: Comparison of disability levels at baseline, immediate post-intervention and 3 months' follow-up (SDS)

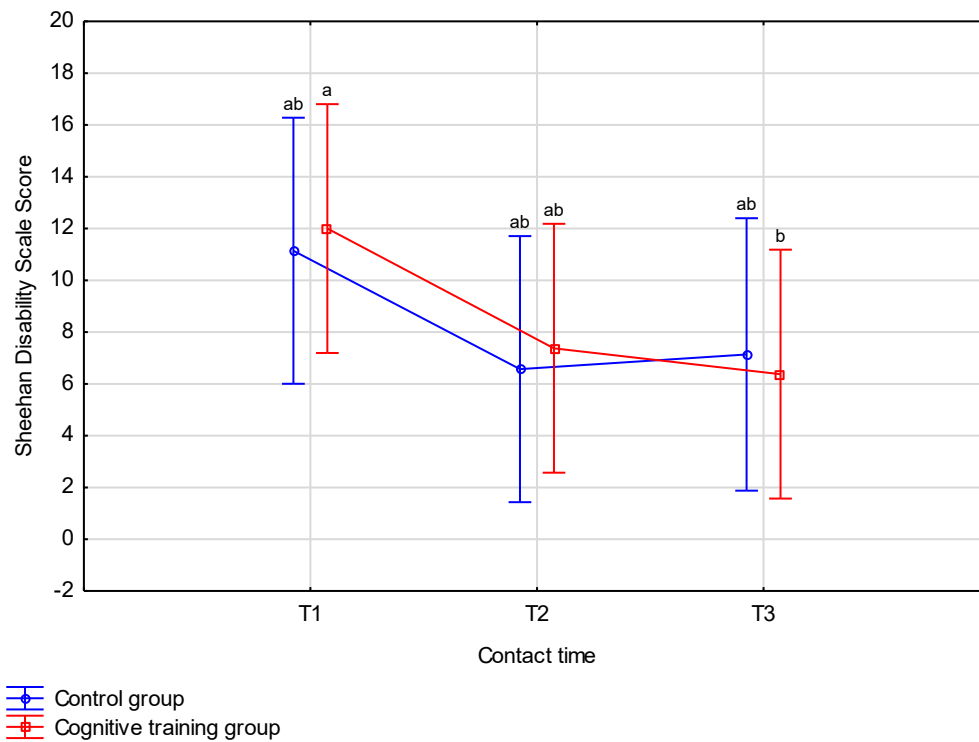


Figure 7: Comparison of work impairment at baseline, immediate post-intervention and 3 months' follow-up (SDS)

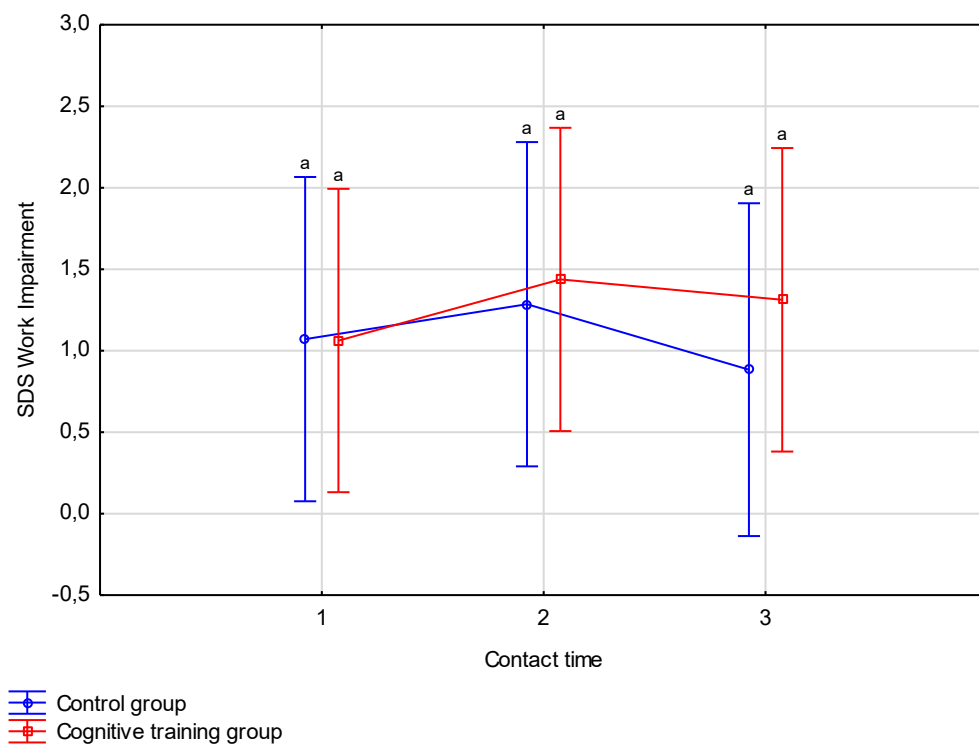


Figure 8: Comparison of social impairment at baseline, immediate post-intervention and 3 months' follow-up (SDS – Social impairment)

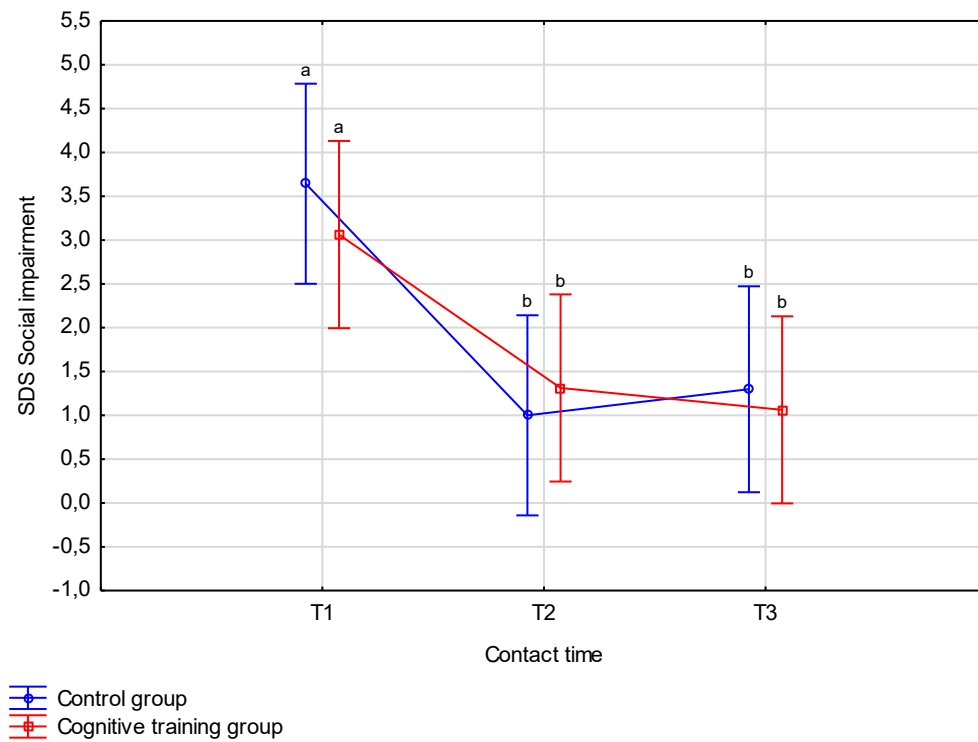


Figure 9: Comparison of family impairment at baseline, immediate post-intervention and 3 months' follow-up (SDS – Family impairment)

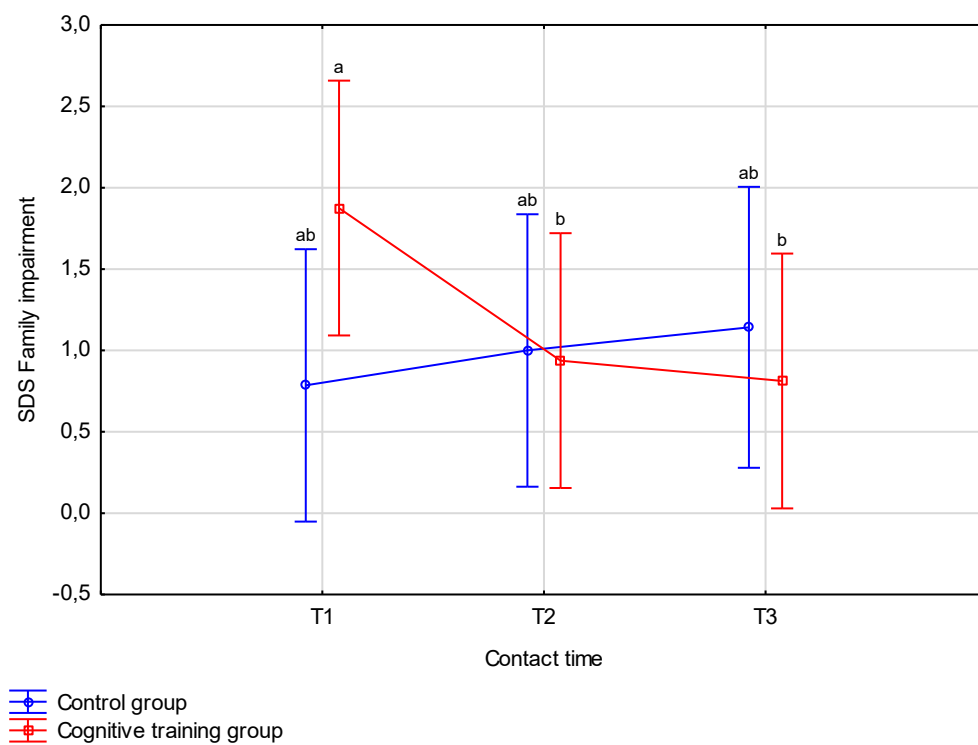


Table 4 - Comparison of general functional impairment at baseline, immediate post-intervention and 3 months' follow-up (SDS: Least Significant Difference Test and Descriptive Statistics)

	T1			T2			T3								
	Mean Diff	Standard Error	p-value	Mean	Standard Error	Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
SDS Total															
CTG	-	-	-	12.0	7.7	4.6	2.3	0.1	7.4	11.5	1.0	2.3	0.7	6.4	10.4
T1 – T3											5.6	2.3	0.02		
PG	-	-	-	11.1	7.6	4.6	2.5	0.1	6.6	10.4	-0.6	2.5	0.8	6.0	8.2
CTG: PG	-0.9	3.5	0.8	-	-	-0.8	3.5	0.8	-	-	0.8	3.6	0.8	-	-
SDS Work impairment															
CTG	-	-	-	1.1	1.34	-0.4	0.5	0.4	1.4	2.4	0.1	0.5	0.8	1.3	2.2
PG	-	-	-	1.1	1.54	-0.2	0.5	0.7	1.3	1.8	0.4	0.5	0.4	0.7	1.3
CTG: PG	0.0	0.7	1.0	-	-	0.2	0.7	0.8	-	-	-0.4	0.7	0.5	-	-
Overall CTG + PG: mean = 1.2 ± 1.8															
SDS Social impairment															
CTG	-	-	-	3.1	2.2	1.8	0.6	<0.001	1.3	2.2	0.3	0.6	0.7	1.1	1.9
PG	-	-	-	3.6	2.8	2.6	0.6	<0.001	1.0	1.8	-0.3	0.6	0.6	1.2	1.7
CTG: PG	0.6	0.8	0.5	-	-	-0.31	0.8	0.7	-	-	0.2	0.8	0.8	-	-

	T1				T2				T3						
	Mean	Standard	p-value	Mean	Standard	Mean	Standard	p-value	Mean	Standard	Mean	Standard	p-value	Mean	Standard
	Diff	Error			Error	Diff*	Error			Deviation	Diff**	Error			Deviation
SDS Family impairment															
CTG	-	-	-	1.9	1.9	0.9	0.5	0.04	0.9	1.4	0.1	0.5	0.8	0.8	1.4
PG	-	-	-	0.8	0.97	-0.2	0.5	0.7	1.0	1.8	-0.1	0.5	0.8	1.0	1.7
Overall PG: mean = 0.93 ± 1.47															
CTG: PG	-1.1	0.6	0.1	-	-	0.1	0.6	0.9	-	-	0.3	0.6	0.6	-	-
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data															

Working Memory

WM was assessed using the LNS and DS subtests of the WAIS-III, as discussed in Chapter 4 (Methodology).

Cognitive Switching

WM ability on the LNS was similar between CTG and PG at T1 (mean difference = 0.5 ± 0.8 , $p = 0.5$), T2 (mean difference = 0.0 ± 0.8 , $p = 1.0$) and T3 (mean difference = 0.6 ± 0.8 , $p = 0.5$). In CTG and PG respectively, there was no significant change from T1 to T2 (CTG: mean difference = 0.6 ± 0.4 , $p = 0.2$; PG: mean difference = 0.0 ± 0.5 , $p = 1.0$) and T3 (CTG: mean difference = -0.1 ± 0.4 , $p = 0.8$; PG: mean difference = -0.7 ± 0.5 , $p = 0.1$). In general, participants scored in the ‘average’ range (mean = 11.0 ± 2.2) on this task (Figure 10; Table 5).

Figure 10: Comparison of working memory at baseline, immediate post-intervention and 3 months’ follow-up (WAIS-III LNS)

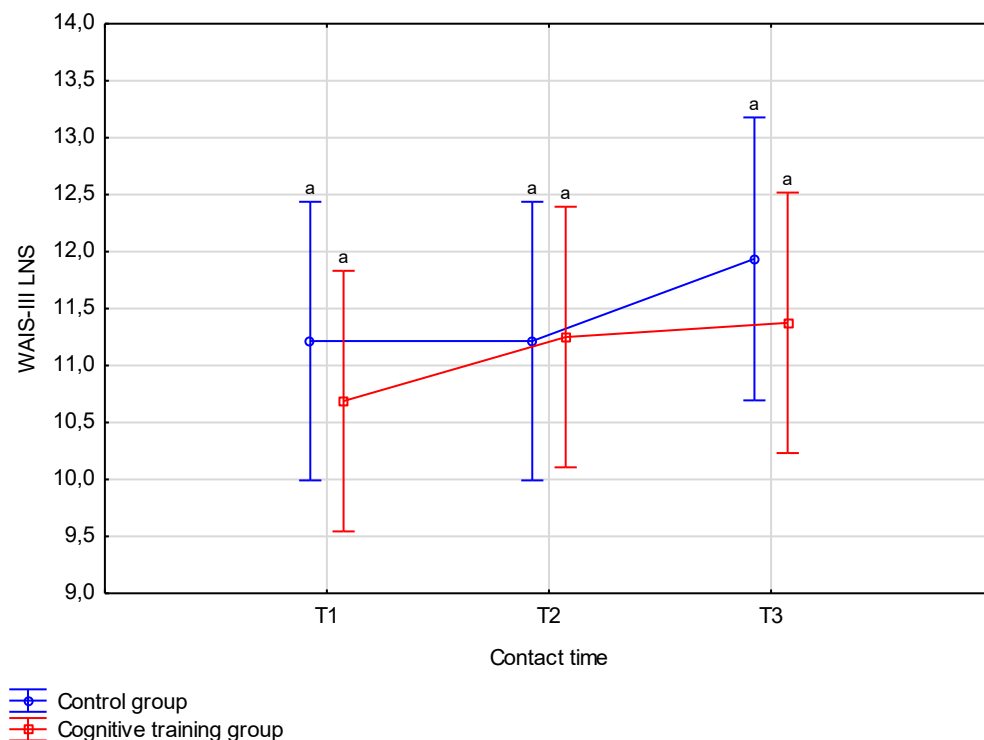


Table 5 - Comparison of working memory – cognitive switching at baseline, immediate post-intervention and 3 months' follow-up (WAIS-III LNS: Least Significant Difference Test and Descriptive Statistics)

	T1			T2			T3								
	Mean Diff	Standard Error	p-value	Mean	Standard Error	Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
CTG	-	-	-	10.7	2.1	-0.6	0.4	0.2	11.3	2.1	-0.1	0.4	0.8	11.4	2.3
PG	-	-	-	11.2	2.1	0.0	0.5	1.0	11.2	2.3	-0.7	0.5	0.1	12.1	2.7
CTG: PG	0.5	0.8	0.5	-	-	0.0	0.8	1.0	-	-	0.6	0.8	0.5	-	-
All participants	-	-	-	10.9	2.1	-	-	-	11.2	2.2	-	-	-	11.7	2.5
Average on LNS according to scaled scores: mean = 11.0 ± 2.2 (WAIS-III South African Norms for the English-speaking population)															
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data															

Repetition of Number List Forwards and Backwards

WM ability on WAIS-III DS showed no significant difference between CTG and PG at T1 (mean difference = -0.2 ± 1.5 , $p = 0.9$), T2 (mean difference = -2.1 ± 1.5 , $p = 0.2$) or T3 (mean difference = 0.3 ± 1.5 , $p = 0.9$) (Figure 11; Table 6).

Participants in the CTG showed significant improvement in WM from T1 (mean = 10.4 ± 2.8 , 'average') to T2 (mean difference = -2.9 ± 0.8 , $p < 0.001$; mean = 12.4 ± 2.9 , 'average'), but did not maintain the improvement (as compared to T1) at 3-month follow-up (mean difference = 1.5 ± 0.8 , $p = 0.1$; mean = 11.5 ± 2.5 , 'average'). PG gradually improved over the duration of the study, with the only significant difference being between T1 and T3 (mean difference = 1.9 ± 0.9 , $p = 0.03$; T1: mean = 10.3 ± 2.4 ; T3: mean = 12.0 ± 2.2 , 'average') (Figure 11; Table 6).

Figure 11: Comparison of working memory – lists backwards at baseline, immediate post-intervention and 3 months' follow-up (WAIS-III DS)

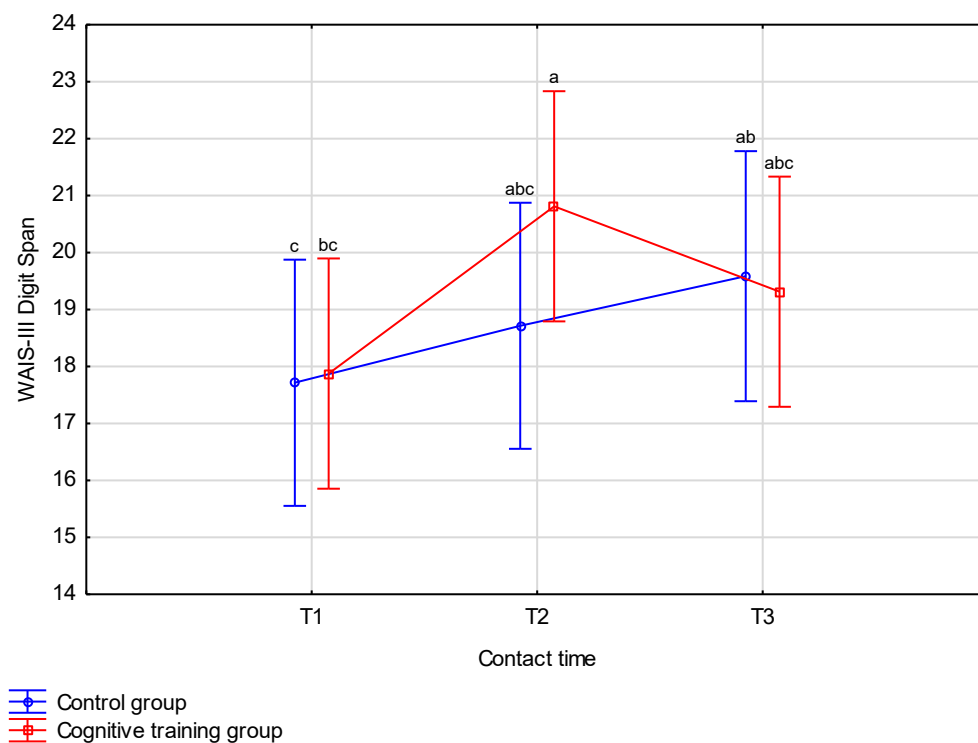


Table 6 - Comparison of working memory at baseline, immediate post-intervention and 3 months' follow-up (WAIS-III DS: Least Significant Difference Test and Descriptive Statistics)

	T1						T2						T3			
	Mean Diff	Standard Error	p-value	Mean	Standard Error		Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
CTG	-	-	-	17.9	4.2		-2.9	0.8	<0.001	20.8	4.3	1.5	0.8	0.1	19.3	4.2
PG	-	-	-	17.7	3.5		-1.0	0.8	0.2	18.7	4.0	-0.9	0.9	0.3	20.1	3.5
CTG: PG	-0.2	1.5	0.9				-2.1	1.5	0.2	-	-	0.3	1.5	0.9	-	-
Scaled scores according to South African norms for the English-speaking population																
CTG	-	-	-	10.4	2.8		-	-	-	12.4	2.9	-	-	-	11.5	2.5
PG	-	-	-	10.3	2.4		-	-	-	10.9	2.6	-	-	-	12.0	2.2
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data																

Impulse Control

IC was assessed using the BISS-11 and SCWT-A, as discussed in Chapter 4 (Methodology). Data obtained using the BISS-11 will be reported on in terms of its 3 second-order factors – i.e. motor impulsiveness (with 2 first-order factors: motor and perseverance), non-planning impulsiveness (with 2 first-order factors: self-control and cognition complexity) and attentional impulsiveness (with 2 first-order factors: attention and cognitive instability).

Motor Impulsiveness

There were no significant differences in motor impulsiveness between the groups or within-groups at the various contact times. The performance remained ‘average’ (Figure 12; Table 7). And neither were there for its first-order factors: motor (Figure 13) and perseverance (Figure 14).

Figure 12: Comparison of motor impulsiveness at baseline, immediate post-intervention and 3 months’ follow-up (BISS-11)

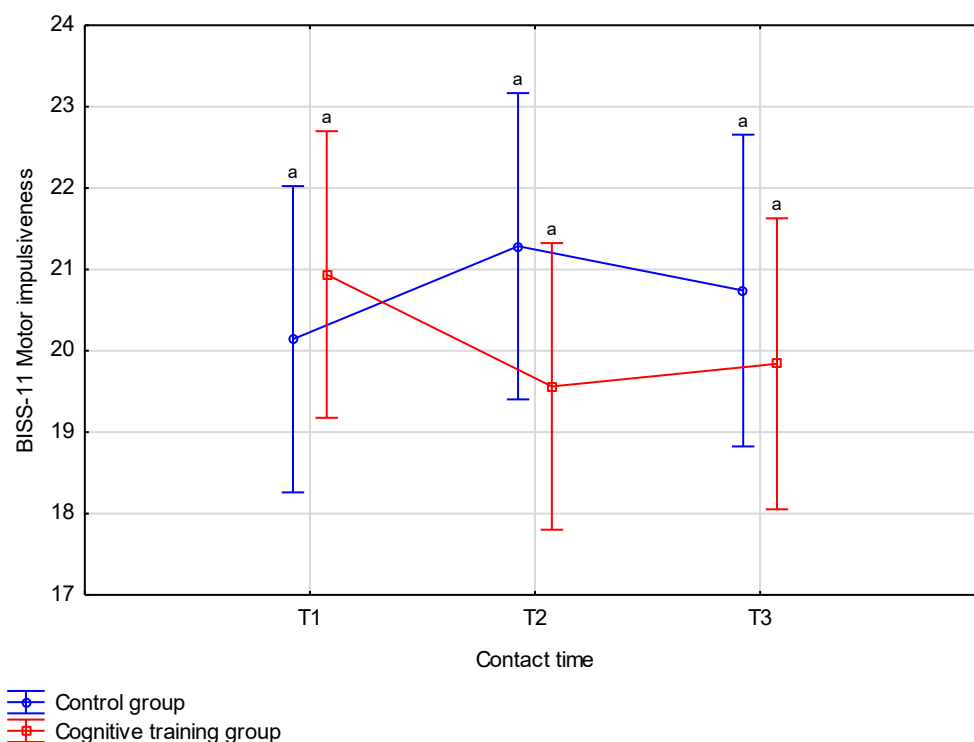


Figure 13: Comparison of motor performance at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

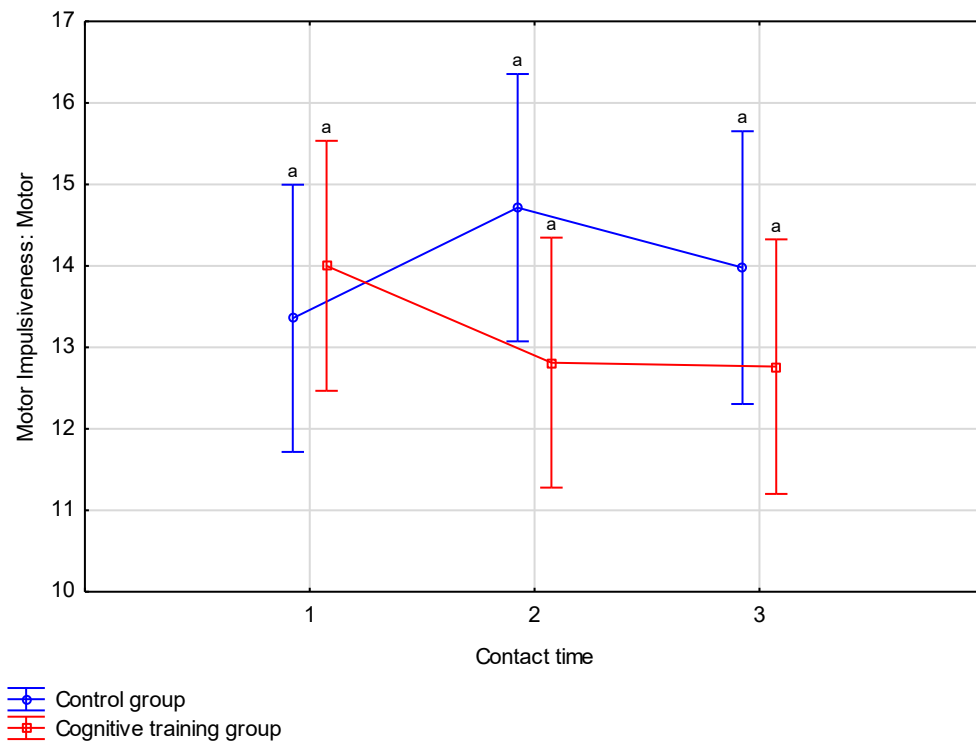
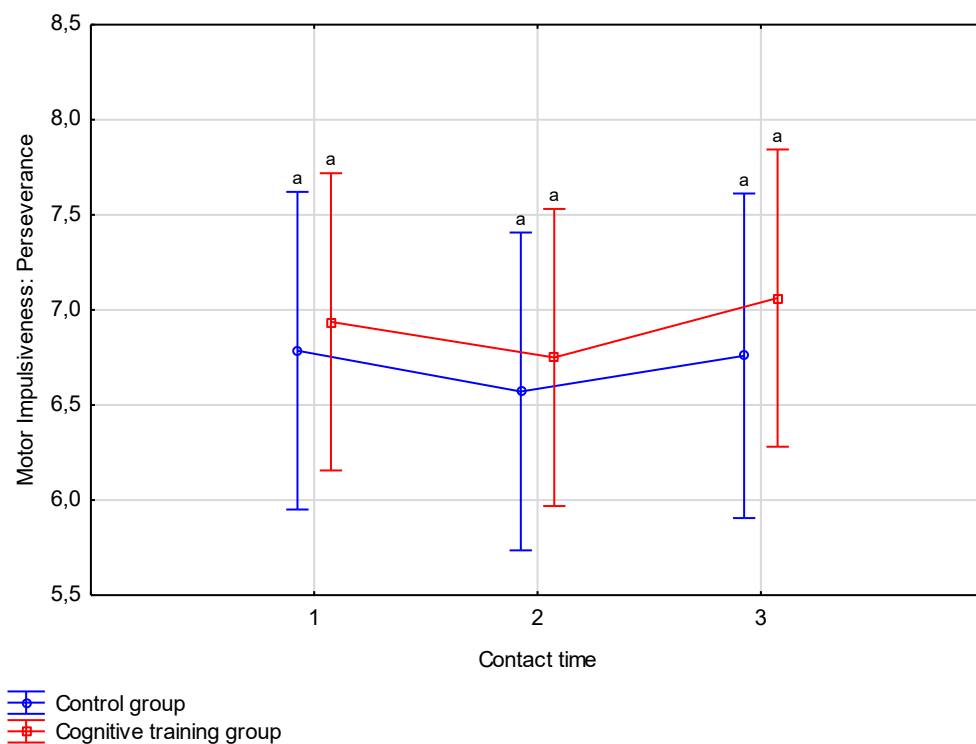


Figure 14: Comparison of motor perseverance at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)



Non-planning Impulsiveness

Non-planning impulsiveness also did not differ or change between the groups or within-groups at the three contact times and remained 'average'. (Figure 15; Table 7). And neither did its first-order factors, self-control (Figure 16) and cognitive complexity (Figure 17).

Figure 15: Comparison of non-planning impulsiveness at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

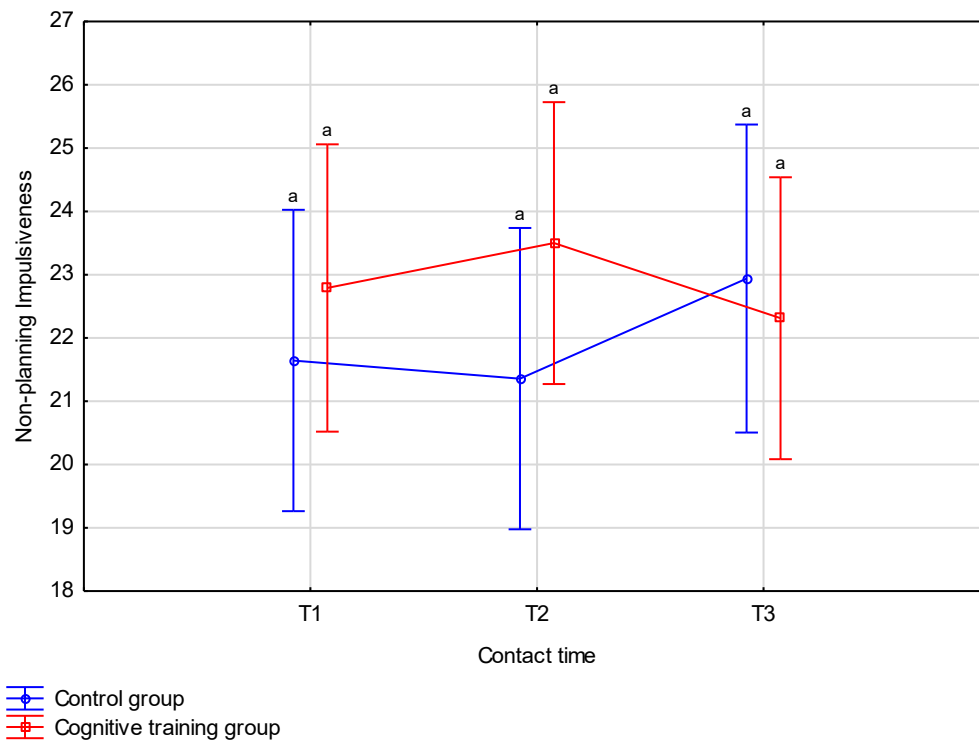


Figure 16: Comparison of self-control at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

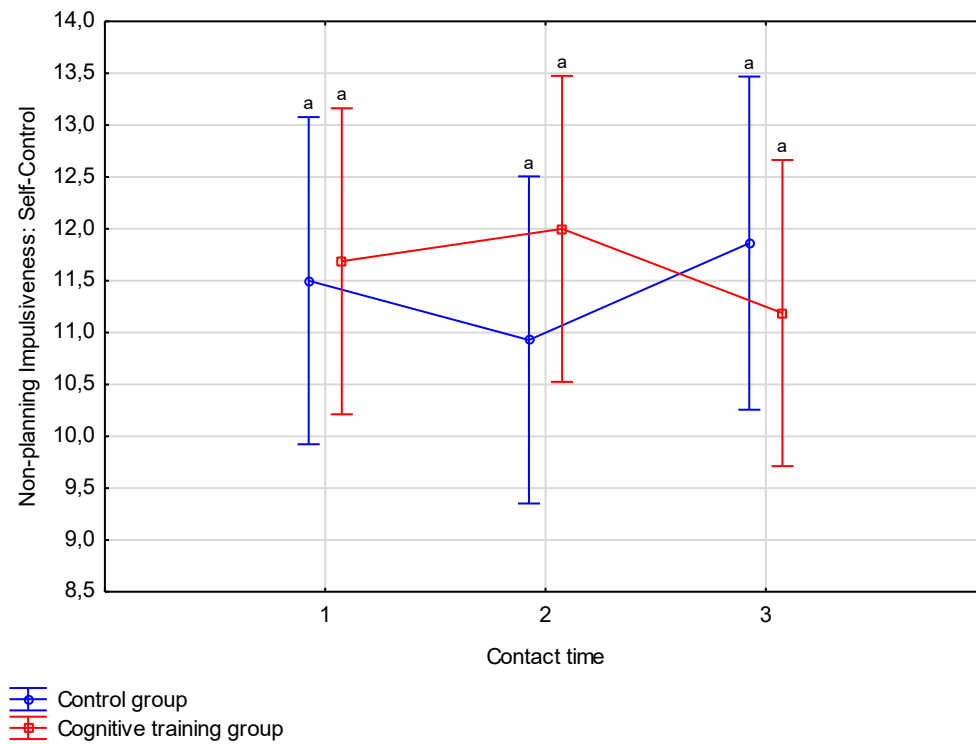
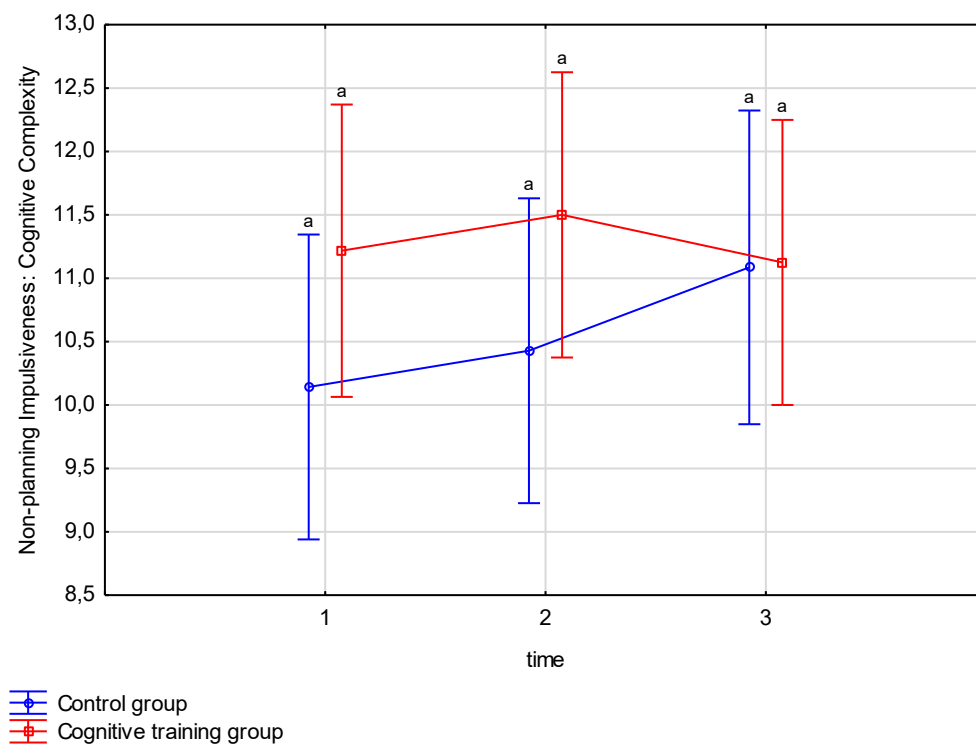


Figure 17: Comparison of cognitive complexity at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)



Attentional Impulsiveness

The one scale that did show some change, was attentional impulsiveness. There was a significant difference between T1 and T3 for CTG (main difference = 2.3 ± 1.1 , $p = 0.02$), suggesting a significant decline in attentional impulsiveness over time. No other significant changes and differences were noted between groups at the different contact times (Figure 18; Table 7). We turn our consideration towards the first-order factors for attentional impulsiveness to better understand where the change took place. Significant changes were highlighted in the CTG i.e. attention (Figure 19) changed significantly between T1 and T3 (main difference = 1.7 ± 0.8 , $p = 0.03$), while cognitive instability (Figure 20) showed a significant decrease from T1 to T2 (main difference = 1.1 ± 0.5 , $p = 0.04$), and again an increase from T2 to T3 (main difference = -1.2 ± 0.6 , $p = 0.04$) for the PG.

Figure 18: Comparison of attentional impulsiveness at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

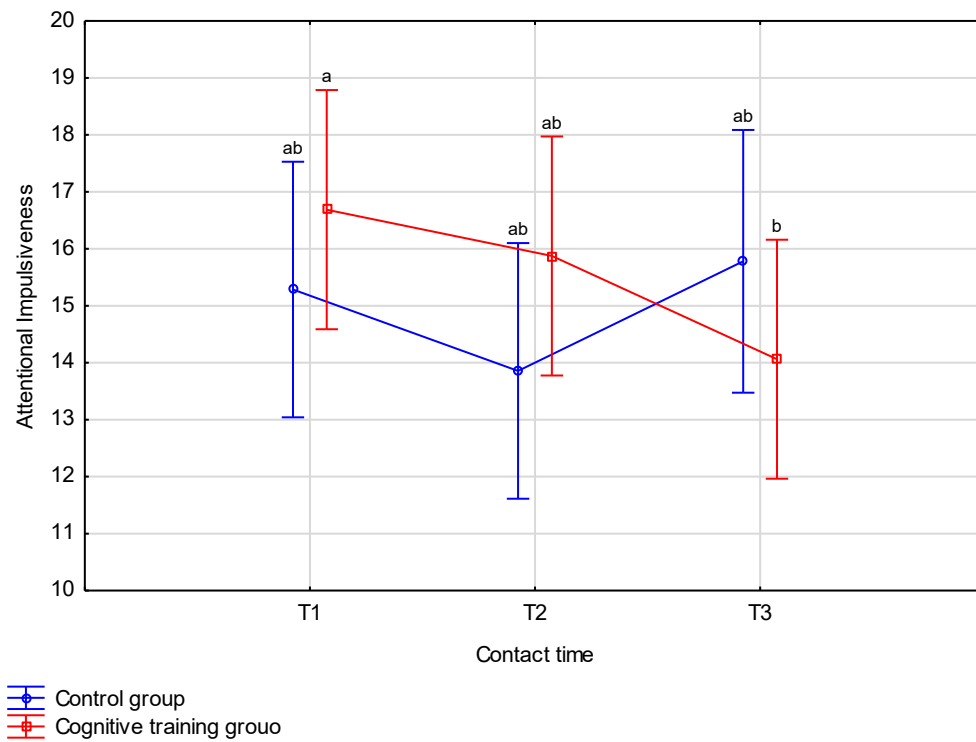


Figure 19: Comparison of attention at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

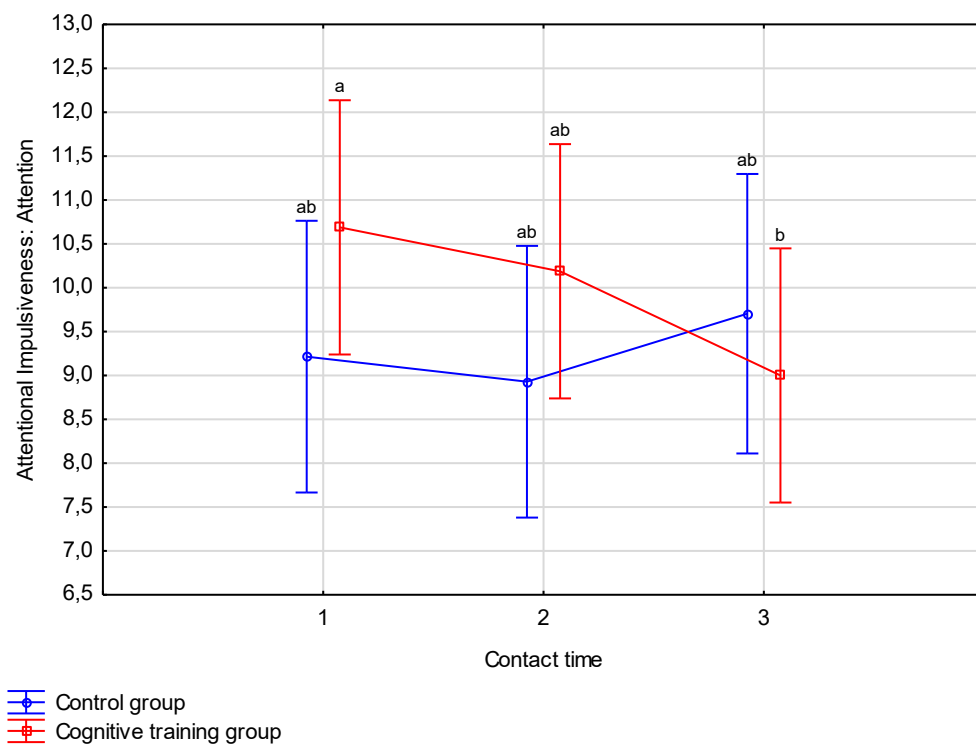


Figure 20: Comparison of cognitive instability at baseline, immediate post-intervention and 3 months' follow-up (BISS-11)

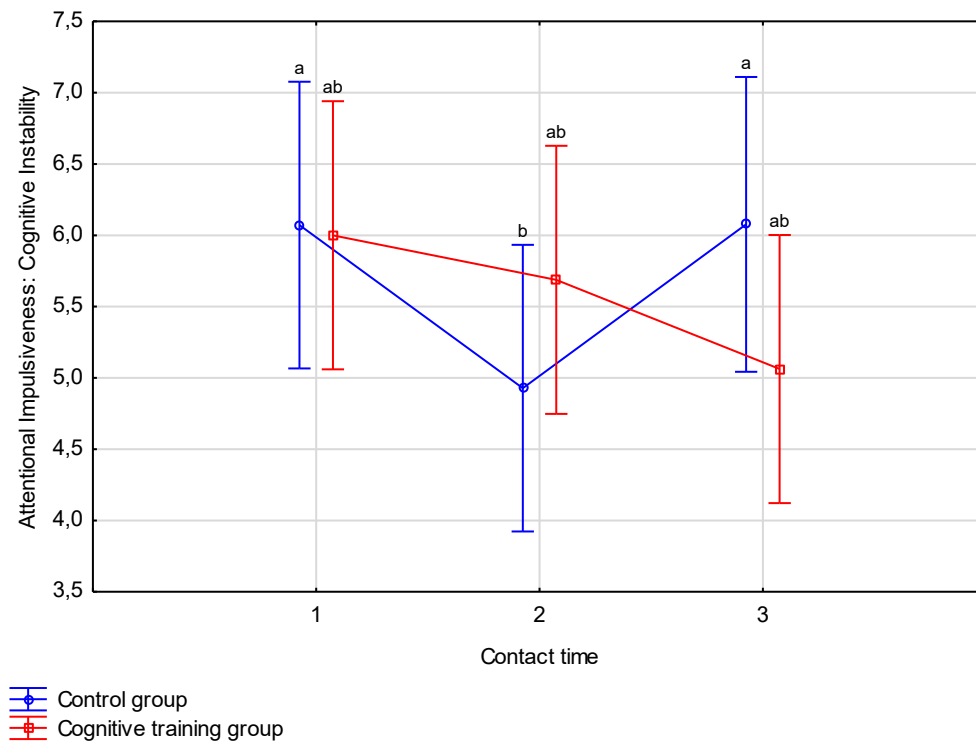


Table 7 - Comparison of motor, non-planning and attentional impulsiveness at baseline, immediate post-intervention and 3 months' follow-up**(BISS-11: Least Significant Difference Test and Descriptive Statistics)**

	T1			T2			T3								
	Mean Diff	Standard Error	p-value	Mean	Standard Error	Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
BISS-11 - Motor impulsiveness (2 nd order factor) [Mean = 20.4 ± 3.5]															
CTG	-	-	-	20.9	3.2	1.4	0.7	0.1	19.6	3.3	-0.3	0.7	0.7	19.7	3.1
PG	-	-	-	20.1	4.2	-1.1	0.8	0.1	21.3	3.6	0.6	0.8	0.5	20.7	3.7
CTG: PG	-0.8	1.3	0.5	-	-	1.7	1.3	0.2	-	-	0.9	1.3	0.5	-	-
BISS-11 – Motor (1 st order factor) [Mean = 13.5 ± 3.1]															
CTG	-	-	-	14.0	2.8	1.2	0.7	0.1	12.8	2.9	0.1	0.7	0.9	12.5	2.8
PG	-	-	-	13.4	3.4	-1.4	0.7	0.1	14.7	3.3	0.7	0.8	0.3	13.9	3.3
CTG: PG	-0.6	1.1	0.6	-	-	1.9	1.1	0.1	-	-	1.2	1.2	0.3	-	-
BISS-11 – Perseverance (1 st order factor) [Mean = 6.8 ± 1.5]															
CTG	-	-	-	6.9	1.4	0.2	0.4	0.6	6.8	1.5	-0.3	0.4	0.4	7.1	1.6
PG	-	-	-	6.8	1.7	0.2	0.4	0.6	6.6	1.3	-0.2	0.4	0.6	6.8	1.8
CTG: PG	-0.2	0.6	0.8	-	-	-0.2	0.6	0.8	-	-	-0.3	0.6	0.6	-	-

	T1					T2					T3				
	Mean	Standard	p-value	Mean	Standard	Mean	Standard	p-value	Mean	Standard	Mean	Standard	p-value	Mean	Standard
	Diff	Error			Error	Diff*	Error			Deviation	Diff**	Error			Deviation
BISS-11 – Non-planning impulsiveness (2 nd order factor) [Mean = 22.4 ± 4.4]															
CTG	-	-	-	22.5	5.0	0.7	1.0	0.5	23.5	4.6	1.2	1.0	0.3	22.3	3.5
PG	-	-	-	21.6	4.5	0.3	1.1	0.8	21.4	4.1	-1.6	1.1	0.2	22.8	4.7
CTG: PG	-1.2	1.6	0.5	-	-	-2.1	1.6	0.2	-	-	0.6	1.7	0.7	-	-
BISS-11 – Self-control (1 st order factor)															
CTG	-	-	-	11.7	3.1	-0.3	0.6	0.6	12.0	3.0	0.8	0.6	0.2	11.2	2.4
PG	-	-	-	11.5	3.1	0.6	0.7	0.4	10.9	3.1	-0.9	0.7	0.2	11.7	3.0
CTG: PG	-0.2	1.1	0.9	-	-	-1.1	1.1	0.5	-	-	0.7	1.1	0.5	-	-
BISS-11 – Cognitive complexity (1 st order factor)															
CTG	-	-	-	11.1	2.5	-0.3	0.6	0.7	11.5	2.3	0.4	0.6	0.5	11.1	1.9
PG	-	-	-	10.1	2.2	-0.3	0.7	0.7	10.4	2.0	-0.7	0.7	0.3	11.1	2.6
CTG: PG	-1.1	0.8	0.2	-	-	-1.1	0.8	0.2	-	-	0.0	0.8	1.0	-	-

	T1						T2						T3					
	Mean	Standard	p-value	Mean	Standard		Mean	Standard	p-value	Mean	Standard		Mean	Standard	p-value	Mean	Standard	
	Diff	Error			Error		Diff*	Error			Deviation		Diff**	Error			Deviation	
BISS-11 - Attentional impulsiveness (2 nd order factor)																		
CTG	-	-	-	16.7	5.5		0.8	1.1	0.5	15.9	4.2		1.8	1.1	0.1	14.1	4.2	
PG	-	-	-	15.3	3.5		1.4	1.2	0.2	13.9	3.5		-1.9	1.2	0.1	15.7	3.8	
CTG: PG	-1.4	1.5	0.4	-	-		-2.0	1.5	0.2	-	-		1.7	1.6	0.3	-	-	
BISS-11 - Attention (1 st order factor)																		
CTG	-	-	-	10.7	3.9		0.5	0.8	0.5	10.2	3.1		1.2	0.8	0.1	9.0	2.6	
T1 – T3													1.7	0.8	0.03			
PG	-	-	-	9.2	2.5		0.3	0.8	0.7	8.9	2.1		-0.8	0.9	0.4	9.6	2.6	
CTG: PG	-1.5	1.1	0.2	-	-		-1.3	1.1	0.8	-	-		0.7	1.1	0.5	-	-	
BISS-11 – Cognitive instability (1 st order factor)																		
CTG	-	-	-	6.0	1.9		0.3	0.5	0.5	5.7	1.7		0.6	0.5	0.2	5.1	2.3	
PG	-	-	-	6.1	1.9		1.1	0.5	0.04	4.9	1.5		-1.2	0.6	0.04	6.1	1.8	
CTG: PG	0.1	0.7	0.9	-	-		-0.8	0.7	0.3	-	-		1.0	0.7	0.2	-	-	
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data																		

Cognitive Interference

Participants in CTG and PG did not differ in terms of their ability to counter cognitive interference at T1 (main difference = 0.2 ± 3.0 , $p = 1.0$), at T2 (main difference = 0.3 ± 3.0 , $p = 0.9$) or T3 (main difference = 2.7 ± 3.1 , $p = 0.4$) (Figure 21; Table 8).

CTG presented with significant increase in their ability to counter cognitive interference from T1 (mean = 53.2 ± 5.6 , 'average') to T2 (main difference = -4.7 ± 2.1 , $p = 0.03$; mean = 57.9 ± 9.8 , 'high average'), which was maintained at T3 (main difference = 1.5 ± 2.1 , $p = 0.5$; mean = 57.0 ± 6.2 , 'high average'). PG also presented with significant increase in their ability to counter interference T1 (mean = 53.4 ± 9.1 , 'average') to T2 (main difference = -4.8 ± 2.2 , $p = 0.03$; mean = 58.1 ± 8.9 , 'high average'), as well as T1 and T3 (main difference = -5.7 ± 2.3 , $p = 0.01$; mean = 58.9 ± 9.1 , 'high average'). The change experienced at T2 thus being maintained at T3 (main difference = -1.0 ± 2.3 , $p = 0.7$) (Figure 21; Table 8).

Figure 21: Comparison of ability to counter cognitive interference at baseline, immediate post-intervention and 3 months' follow-up (SCWT-A)

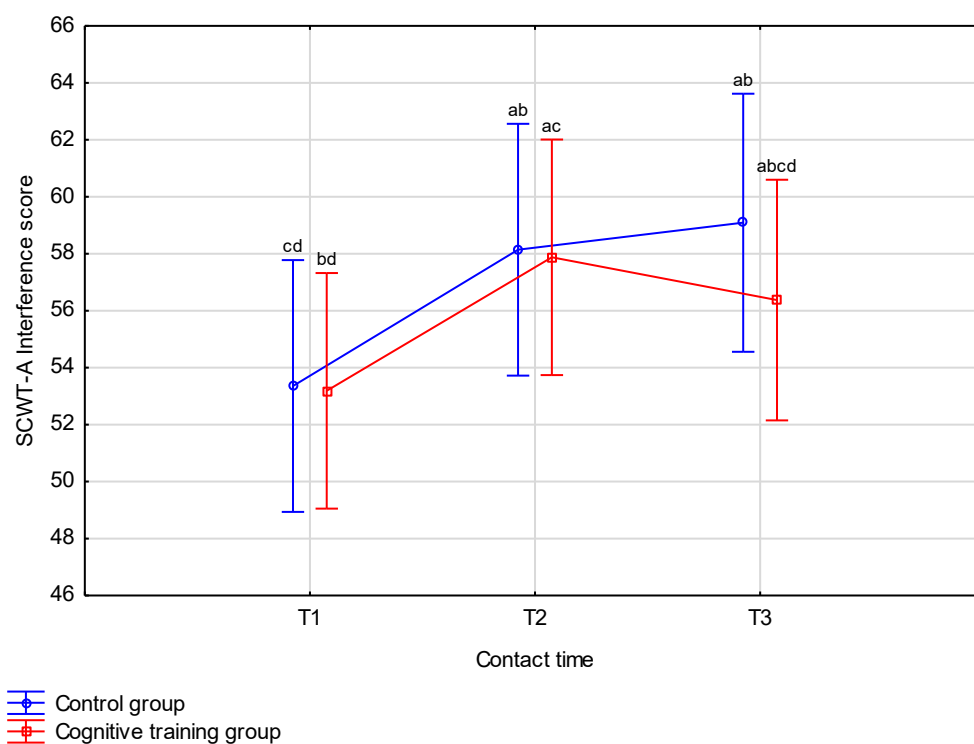


Table 8 - Comparison of cognitive interference at baseline, immediate post-intervention and 3 months' follow-up (SCWT-A: Least Significant Difference Test and Descriptive Statistics)

	T1			T2			T3								
	Mean Diff	Standard Error	p-value	Mean	Standard Error	Mean Diff*	Standard Error	p-value	Mean	Standard Deviation	Mean Diff**	Standard Error	p-value	Mean	Standard Deviation
CTG	-	-	-	53.2	5.6	-4.7	2.1	0.03	57.9	9.8	1.5	2.1	0.5	57.0	6.2
PG	-	-	-	53.4	9.1	-4.8	2.2	0.03	58.1	8.9	1.0	2.3	0.7	58.9	9.1
CTG: PG	0.2	3.0	1.0	-	-	0.3	3.0	0.9	-	-	2.7	3.1	0.4	-	-
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data															

Emotional Regulation

ER was assessed by the ARS and the DERS. A detailed account of these measuring instruments is included in Chapter 4 (Methodology). Both scales were included as they measure different aspects of ER which may be relevant in this context.

Ability to Control Emotions

With regards to participants' ability to control their emotions, there were no significant differences between the CTG and PG at T1, T2 and T3, and neither were there significant within-group changes noted from T1 through to T3. Participants in both groups reported that they could control their emotions *most of the time*, at T1, T2 and T3 (mean = 20.2 ± 5.5) (Figure 22; Table 9).

The Belief of Causal Link between Emotions and Hair-pulling

When assessing the belief that their emotions are linked to hair-pulling, there was no significant difference between participants' perceptions at any of the contact times (T1: mean difference = -0.8 ± 1.8 , $p = 0.7$; T2: mean difference = 0.5 ± 1.8 , $p = 0.8$; T3: mean difference = -3.4 ± 1.8 , $p = 0.1$). Participants in the PG had significantly less confidence in the causal link between their emotions and hair-pulling at T3, compared to T1 (mean difference = 2.9 ± 1.2 , $p = 0.02$) (Figure 23; Table 9).

Figure 22: Comparison of participants' reflection on emotional control at baseline, immediate post-intervention and 3 months' follow-up (ARS - Control)

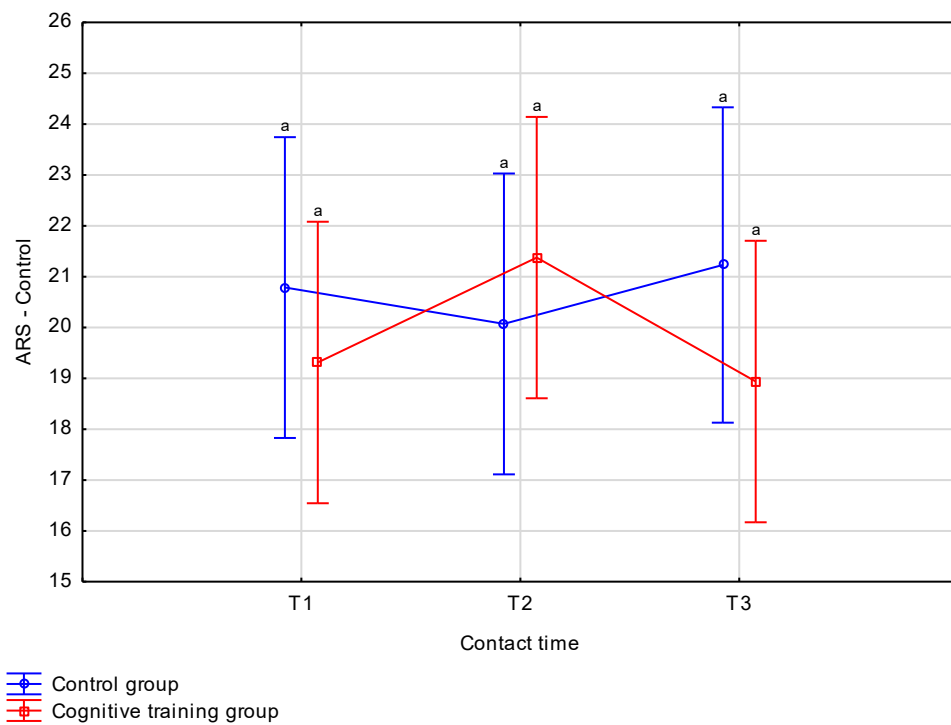


Figure 23: Comparison of participant understanding of emotions causing hair-pulling at baseline, immediate post-intervention and 3 months' follow-up (ARS - Cause)

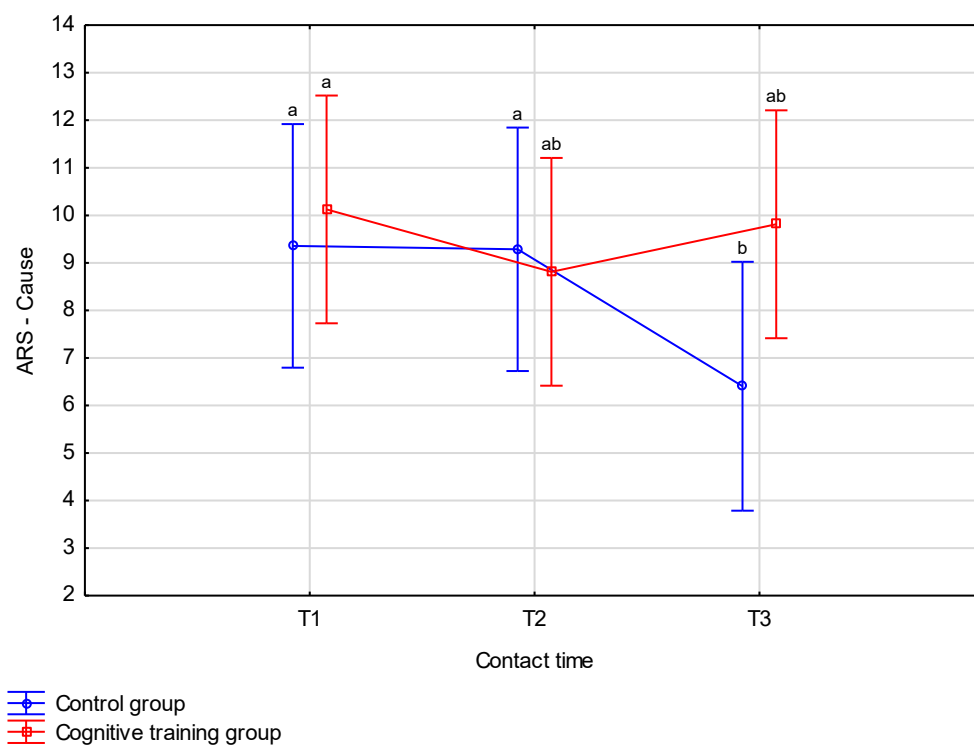


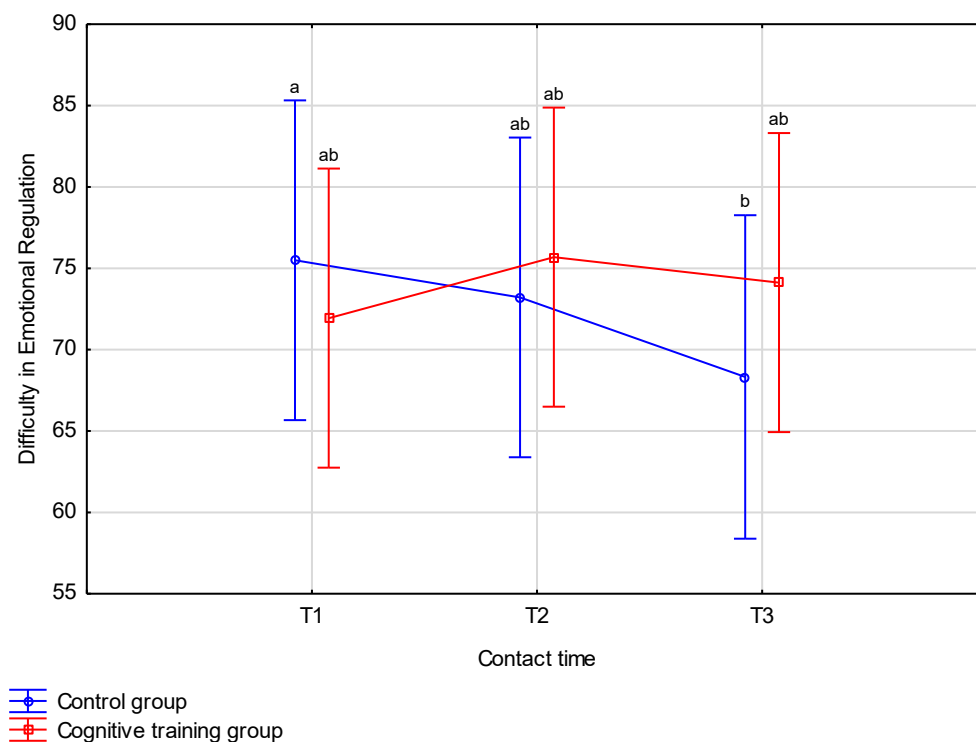
Table 9 - Comparison of participant understanding of emotional control and emotions causing hair-pulling at baseline, immediate post-intervention and 3 months' follow-up (ARS: Least Significant Difference Test and Descriptive Statistics)

	T1			T2			T3		
	Mean Diff	Standard Error	p-value	Mean	Standard Error	Mean Diff*	Standard Error	Mean Diff**	Standard Error
ARS - Control									
CTG	-	-	-	19.3	4.9	-2.1	1.3	2.4	1.3
PG	-	-	-	20.8	6.6	0.7	1.4	-1.2	1.5
CTG: PG	1.5	2.0	0.5	-	-	-1.3	2.0	2.3	2.1
ARS - Cause									
CTG	-	-	-	10.1	5.1	1.3	1.1	-1.0	1.1
PG	-	-	-	9.4	3.5	0.1	1.2	2.9	1.2
CTG: PG	-0.8	1.8	0.7	-	-	0.5	1.8	-3.4	1.8
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data									

General Difficulty in Emotional Regulation Scale

In general, participants experienced difficulty in ER 'sometimes' (mean = 73.0 ± 18.0 ; 40.6%). The only significant difference in results was for PG from T1 to T3 (main difference = 7.2 ± 3.3 , $p = 0.03$; mean = 66.6 ± 21.7 ; 37.0%) (Figure 24; Table 10).

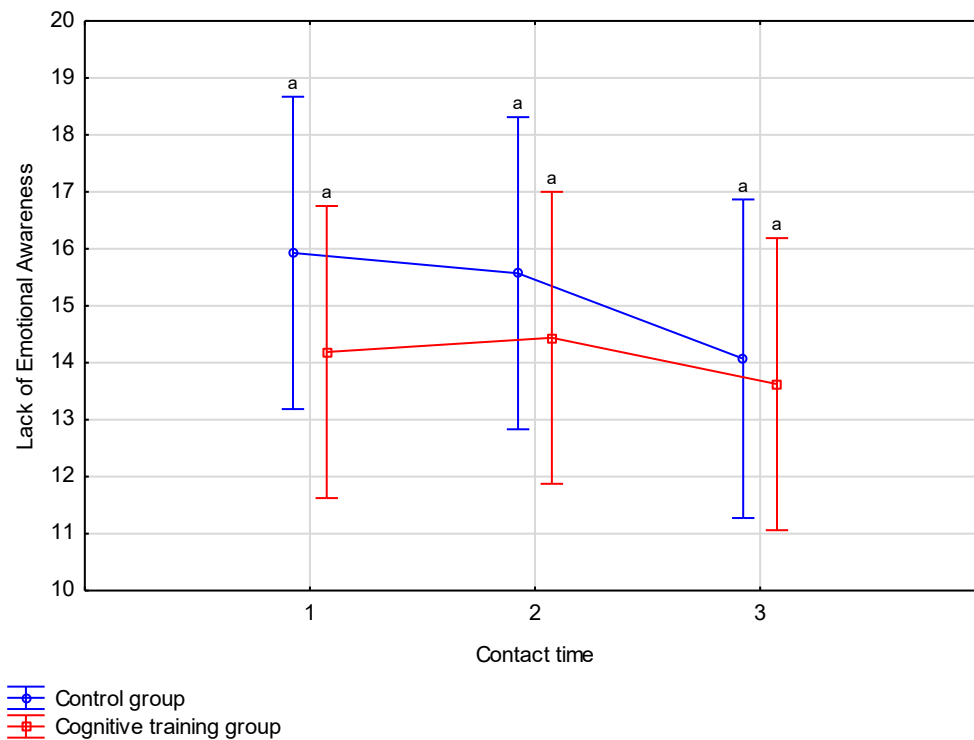
Figure 24: Comparison of emotional regulation difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Lack of Emotional Awareness

In general, there were no significant differences between CTG and PG, or changes at contact times for the groups respectively. Participants experienced lack of emotional awareness 'about half of the time' (mean = 14.5 ± 5.0 ; 48.5%) (Figure 25, Table 10).

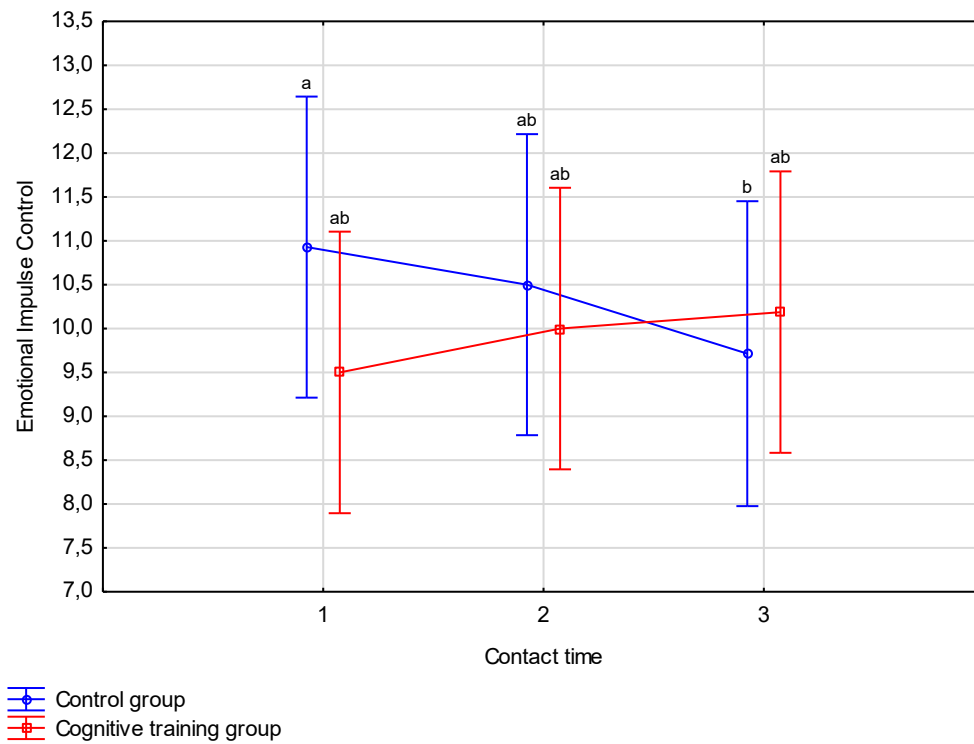
Figure 25: Comparison of lack of emotional awareness difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Emotional Impulse Control Difficulties

There were no significant differences between CTG and PG at any of the contact times. CTG presented with no significant changes during the study and in general reported experiencing emotional IC difficulties '*sometimes*' (mean = 9.9 ± 2.7 ; 48.5%). There was a significant difference in results for PG from T1 to T3 (main difference = 1.2 ± 0.6 , $p = 0.1$), which resulted in emotional IC difficulties changing from '*about half of the time*' (T1: mean = 10.9 ± 3.7 ; 36.4%) to '*sometimes*' (T3: mean = 9.5 ± 3.6 ; 31.5%) (Figure 26, Table 10).

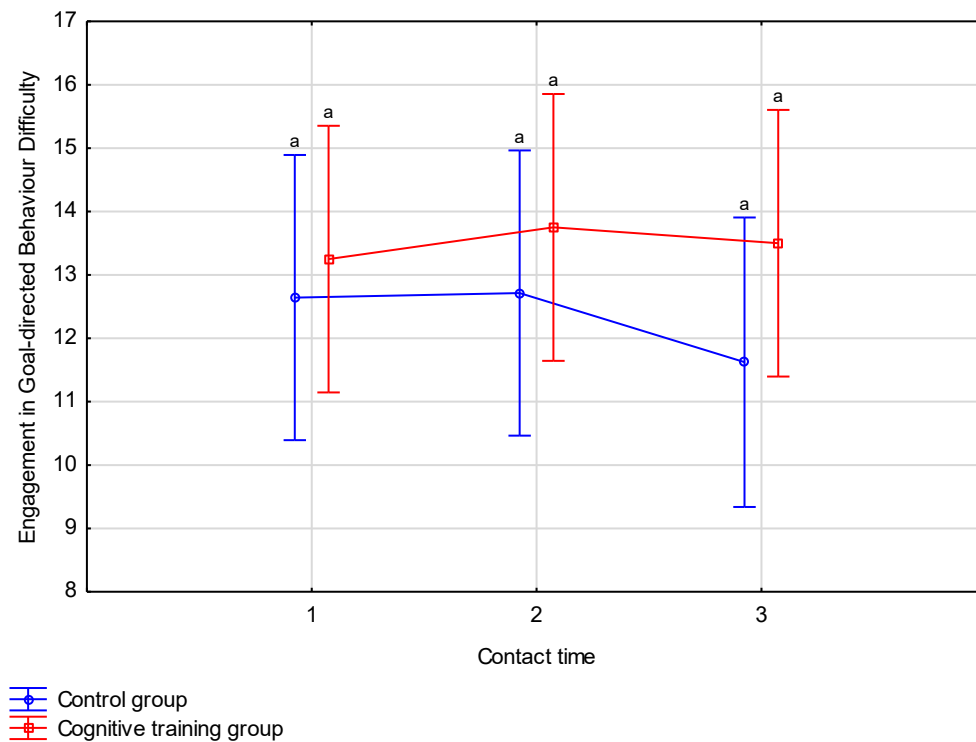
Figure 26: Comparison of emotional impulse control difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Difficulties Engaging in Goal-directed Behaviour

In general, there were no significant differences between CTG and PG, or changes at contact times for the groups respectively. Participants experienced difficulty engaging in goal-directed behaviour '*about half of the time*' (mean = 13.0 ± 4.2 ; 43.2%) (Figure 27, Table 10).

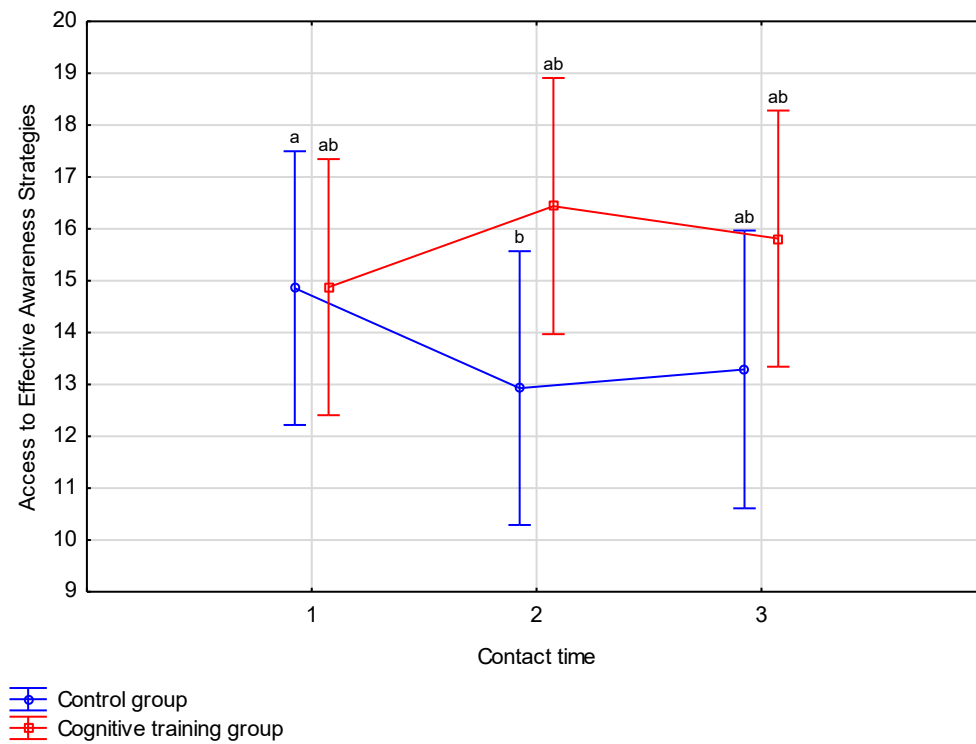
Figure 27: Comparison of engaging in goal-directed behaviour difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Limited Access to Effective Emotional Regulation Strategies

There were no significant differences between CTG and PG at any of the contact times (T1: mean difference = 0.0 ± 1.8 , $p = 1.0$; T2: mean difference = -3.5 ± 1.8 , $p = 0.1$; T3: mean difference = -2.5 ± 1.8 , $p = 0.2$). CTG presented with no significant changes during the study and in general reported experiencing limited access to effective ER strategies '*about half of the time*' (mean = 15.7 ± 5.0 , 52.4%). There was a significant reduction in experience for PG from T1 to T2 (main difference = 1.9 ± 1.0 , $p = 0.05$). However, the range remained the same and limited access to effective ER strategies remained '*about half of the time*' at T1 (mean = 14.9 ± 5.0 ; 49.5%), T2 (mean = 12.9 ± 4.4 ; 43.1%) and remained in that range at T3 (mean = 12.9 ± 4.7 ; 43.0%) (Figure 28, Table 10).

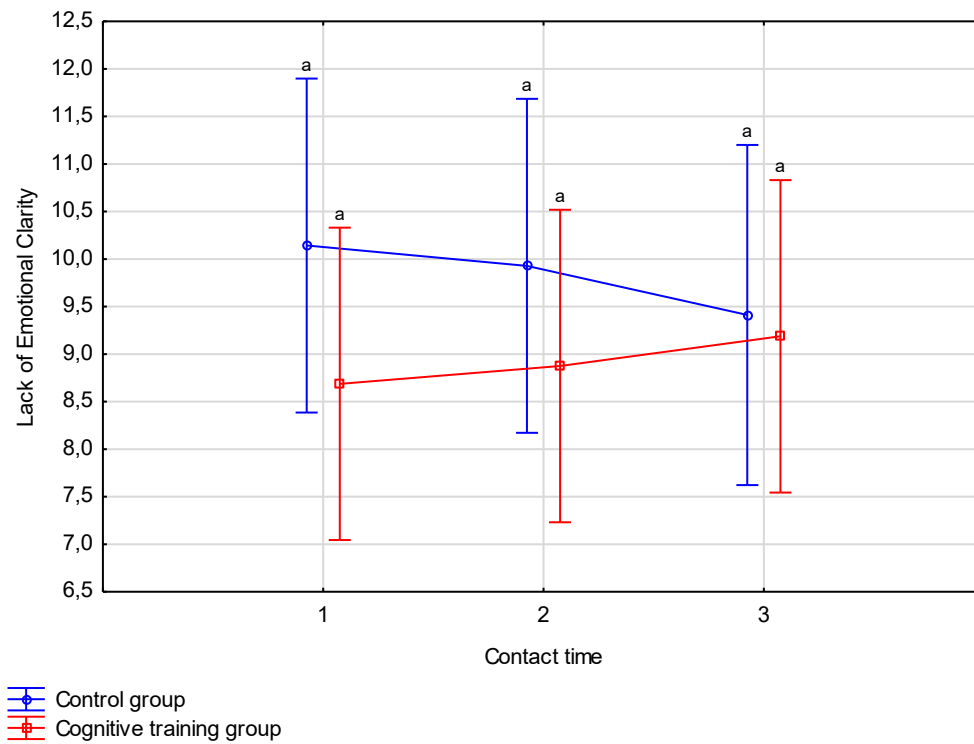
Figure 28: Comparison of access to effective emotional regulation strategies difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Lack of Emotional Clarity

In general, there were no significant differences between CTG and PG, or changes at contact times for the groups respectively. Participants experienced lack of emotional clarity 'sometimes' (mean = 9.3 ± 3.2 ; 31.0%) (Figure 29, Table 10).

Figure 29: Comparison of lack of emotional clarity difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS)



Non-acceptance of Emotional Responses

In general, there were no significant differences between CTG and PG, or changes at contact times for the groups respectively. Participants experienced non-acceptance of emotional responses '*about half the time*' (mean = 11.4 ± 4.5 ; 37.9%) (Figure 30, Table 10).

Figure 30: Comparison of non-acceptance of emotional responses at baseline, immediate post-intervention and 3 months' follow-up (DERS)

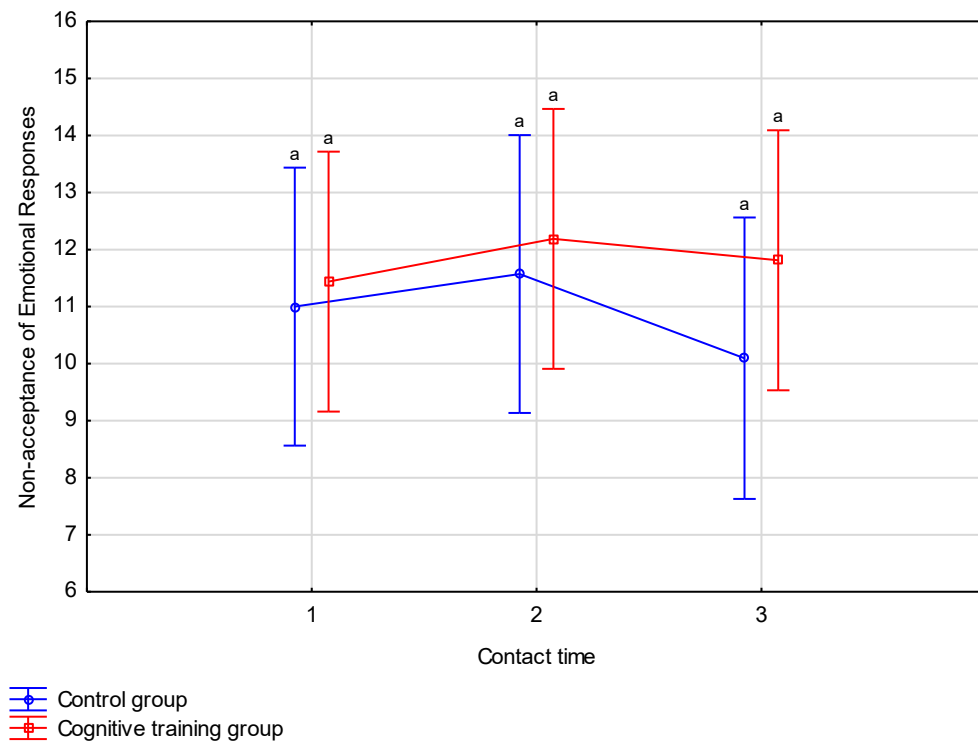


Table 10 - Comparison of emotional regulation difficulty at baseline, immediate post-intervention and 3 months' follow-up (DERS: Least Significant Difference Test and Descriptive Statistics)

	T1					T2					T3				
	Mean Diff	Standard Error	p- value	Mean	Standard Deviation	Mean Diff*	Standard Error	p- value	Mean	Standard Deviation	Mean Diff**	Standard Error	p- value	Mean	Standard Deviation
Overall – all subscales included															
CTG	-	-	-	71.9	12.4	-3.8	3.0	0.2	75.7	16.7	1.6	3.0	0.6	74.1	19.0
PG	-	-	-	75.5	19.7	2.3	3.2	0.5	73.2	19.6	4.9	3.3	0.1	66.6	21.7
CTG: PG	3.6	6.7	0.6	-	-	-2.5	6.7	0.7	-	-	-5.8	6.8	0.4	-	-
Lack of Emotional Awareness															
CTG	-	-	-	14.2	3.8	-0.3	1.1	0.8	14.4	4.2	0.8	1.1	0.5	13.6	4.8
PG	-	-	-	15.9	6.6	0.4	1.2	0.8	15.6	5.7	1.5	1.2	0.2	13.6	5.3
CTG: PG	1.7	1.9	0.4	-	-	1.1	1.9	0.6	-	-	0.5	1.9	0.8	-	-
Overall CTG+PG: Mean = 14.54 ± 5.02															
Impulse Control Difficulties															
CTG	-	-	-	9.5	2.6	-0.5	0.6	0.4	10.0	2.8	-0.2	0.6	0.7	10.2	2.7
Overall CTG: Mean = 9.9 ± 2.7															
PG	-	-	-	10.9	3.7	0.4	0.6	0.5	10.5	3.7	0.8	0.6	0.2	9.5	3.6
T1 – T3											1.2	0.6	0.05		
CTG: PG	1.4	1.2	0.2	-	-	0.5	1.2	0.7	-	-	-0.5	1.2	0.7	-	-

	T1						T2						T3		
	Mean	Standard	p-	Mean	Standard		Mean	Standard	p-	Mean	Standard		Mean	Standard	
	Diff	Error	value		Deviation		Diff*	Error	value		Deviation		Diff**	Error	value
Difficulties Engaging in Goal-directed Behaviour															
CTG	-	-	-	13.3	3.9		-0.5	0.8	0.8	13.8	5.3		0.3	0.8	0.8
PG	-	-	-	12.6	3.0		-0.1	0.8	0.9	12.7	3.7		1.1	0.9	0.2
CTG: PG	-0.6	1.5	0.7	-	-		-1.0	1.5	0.5	-	-		-1.9	1.6	0.2
Overall CTG+PG: Mean = 13.0 ± 4.2															
Limited Access to Emotional Regulation Strategies															
CTG	-	-	-	14.9	4.8		-1.6	0.9	0.1	16.4	5.7		0.6	0.9	0.5
Overall CTG: Mean = 15.7 ± 5.0															
PG	-	-	-	14.9	5.0		1.9	1.0	0.05	12.9	4.4		-0.4	1.0	0.7
CTG: PG	-0.0	1.8	1.0	-	-		-3.5	1.8	0.06	-	-		-2.5	1.8	0.2
Lack of Emotional Clarity															
CTG	-	-	-	8.7	2.9		-0.2	0.7	0.8	8.9	3.3		-0.3	0.7	0.7
PG	-	-	-	10.1	2.7		0.2	0.7	0.8	9.9	3.1		0.5	0.7	0.5
CTG: PG	1.5	1.2	0.2	-	-		1.1	1.2	0.4	-	-		0.2	1.2	0.9
Overall CTG+PG: Mean = 9.31 ± 3.23															
Non-acceptance of Emotional Responses															
CTG	-	-	-	11.4	3.7		-0.8	0.8	0.3	12.2	4.3		0.4	0.8	0.6
PG	-	-	-	11.0	5.8		-0.6	0.8	0.5	11.6	5.2		1.5	0.9	0.1
CTG: PG	-0.4	1.7	0.8	-	-		-0.6	1.7	0.7	-	-		-1.7	1.7	0.3
Overall CTG+PG: Mean = 11.4 ± 4.5															
CTG: Cognitive training group; PG: Control group; * Mean difference between T1 and T2 data; ** Mean difference between T2 and T3 data															

Brief Chapter Overview

The chapter provided quantitative data of participants' report of HPS and clinicians' report of participants' illness severity. The impact of HPD on general functioning and disability due to HPD were also investigated. Participant performance on WM, IC and ER were assessed at T1, T2 and T3, for both CTG and PG, and compared for significant changes and differences across the 3 different contact times.

CWMT significantly decreased hair-pulling severity compared to the control condition. Participants did not demonstrate notable impairments in WM, IC, and ER at baseline, and CWMT did not have greater impact on IC and ER than the control condition. WM did improve immediately post-training, but the improvement was not maintained at 3-month follow-up.

The next chapter, Chapter 6, will depict data obtained using qualitative methods.

*“Because it has become so second nature, it has been so difficult to stop.
That’s why I am concerned about it because it is not just something that I
can switch on and off...”*

Research Participant

Chapter 6: Results - Qualitative Data

Introduction

Qualitative data were collected to gain a more in-depth understanding of participants' experience of HPD, and to inform the feasibility and acceptability of cognitive training as a treatment modality. In this chapter the themes that arose during interviews with participants are presented, each with supporting quotations from interview transcriptions. Discussion of the themes and links to existing literature will follow in Chapter 6 (Discussion). As discussed in Chapter 4 (Methodology), the qualitative data were analyzed using an interpretative phenomenological approach (Creswell, 2012; Lester, 1999). This approach consists of familiarization and immersion, introducing themes, coding, elaboration, interpretation and checking, and lastly integration of the information into a final report (TerreBlanche et al., 2010). A computer-assisted qualitative data analysis software program, i.e. Atlas.ti 8.1.30 was used in the analysis.

The chapter is divided according to the three contact sessions with participants in both groups (i.e. screening and orientation session, T1; immediate post-intervention, T2 and 3 months post-intervention, T3). For each contact session, the emerging themes are discussed.

Contact 1: Screening and Orientation Session – The Experience of Living with Hair-pulling Disorder

In total, 37 interviews were included from the screening and orientation session (first contact/T1). During the first interview with participants, the questions from which the interview flowed were as follow:

“Tell me about life with Trichotillomania?” and “How would life be different without Trichotillomania?”

The 5 main themes identified were:

- Theme 1: Hair-pulling experience
- Theme 2: Emotions
- Theme 3: Relationships
- Theme 4: Interventions
- Theme 5: Self

Each of the main themes is divided into subthemes and supporting quotations from interviews are provided.

Theme 1: Hair-pulling Experience

The responses of participants regarding their experience of hair-pulling sessions are summarised in the following section under the subthemes: 1) triggers and pulling behaviours, 2) onset 3) the immediate impact of pulling and 4) insight.

Subtheme 1: Triggers and Pulling Behaviours

Situational triggers: Some participants reported behaviours which started unintentionally, like pulling out a stray hair or looking for split ends, became a habit and part of the daily routine. In general, the behaviour was reported to be better controlled when amongst people, e.g. in the work or school environment. Although some participants were able to control the urge in these situations, pulling was often in the back of their minds. Most participants reported that pulling has never gone away completely but was often reported as being less of an issue during holidays or when travelling. Many participants described avoiding relaxation time ('downtime') because then they were more prone to pull. Studying, reading, writing, driving, speaking on the phone, watching television, lying in bed or being in deep thought, were all noted as situations of vulnerability – when the pulling was most likely to take place. One participant paralleled the pulling experience to eating popcorn – once started, it was

challenging to stop. Another participant described a pulling episode as a trance-like state or that she zoned out.

Emotions maintaining pulling: There was ambivalence amid some participants whether they truly wanted to stop the behaviour. On the one hand, there was a sense of the behaviour not being in their best interest or socially appropriate. On the other hand, most participants felt pulling brought a sense of satisfaction and relief. There were reports that delayed pulling at times lead to more intense pulling at a later stage.

Sites and ways of pulling: Participants reported different ways of pulling hair – hands, tweezers; as well as different ways of discarding hair (e.g. pulling through teeth, lips or fingers, investigating it closely - against the light or against a white surface, eating the hair, rolling it in a ball, throwing the hair on the floor or out the window, or collecting and saving the hair). The site of hair pulling could also change and differed amongst participants. There were also different types of hair being pulled, although they were usually the curly, kinky, thicker or grey ones. One participant commented that she pulled others' hair.

Table 11 - Theme 1: Hair-pulling experience - Subtheme 1: Triggers and pulling behaviours

“And then it will carry on until, and then there will be brief periods when I stop because there will be so much hair on the floor, ‘because I have pulled out so much hair. I will then play with one hair but that sensation that I get after I pull my hair just is not the same and I need to get that again, so I will just discard that, throw it away, and start from scratch.” (Participant 04).

“Is nie net wanneer ek angstig is nie, maar ek moet, ek doen dit dan net wanneer ek op die telefoon praat, as ek sit en praat of as ek, so TV kyk, so h’m, maar wanneer daar ’n probleem of iets is wat my h’m, wat ek bekommerd oor, of stres oor dan lyk dit dan is ek eers erg.” *[It isn’t only when I am anxious, but I have to, I do it when I am on the phone, if I sit and talk, or if I am watching TV. But when there is a problem or something that worries me*

or that I stress about, then I am really bad.] (Participant 05)

“Ek wil partykeer nie die urge oorkom nie. Ek, ek wil daai gevoel het van my hare uittrek.”
[Sometimes I do not want to overcome the urge to pull. I want that feeling of pulling my hair.]
 (Participant 09)

“Maar die impuls h’m, is net van so aard dat ek gee nie om nie.” *[But the impulse is of such a nature, that I do not care.]* (Participant 10)

“I think that I am able to compartmentalise it. Part of me, thinks, take me as how I am. There are mixed feelings I suppose. On the one hand, I should pull myself together, control myself, get over it, you know. It’s been so many years and the other part of me says if you don’t like it - tough! I do have both of those feelings. I can, when I have a really bad hair pulling episode, where there is hair everywhere and because my hair is grey, it shows. So, if I am over a dark top, there is hair everywhere. And there is always hair around me and that is horrible, it’s not falling out naturally. There is never hair in my brush because my hair doesn’t have time to fall out naturally. But there is pulled hair everywhere and I know its mine ‘because there will be a root on it.” (Participant 12)

“Ek wil dit baie graag verander, h’m, ja, dit voel vir my asof ek, want ek het nog nooit amper so iemand ontmoet nie, leer ken nie. So, ek wil, dit voel vir my asof ek die enigste een in die wêreld is en dat ek net weet daar is nog geen hulp vir dit nie.” *[I want to change it very badly, h’m, yes, it feels to me as though, because I’ve almost never met, or gotten to know someone like this. So, I want, it feels like I am the only one in the world and that I just know there is no help for it]* (Participant 16)

“Ya, look, it does feel good. I don’t know whether I am just not stopping because it feels good or um... or whether this is some kind of psychological or subconscious outlet. I allow

myself not to give in to my natural tendency to control, I just let it go, I just pull. Maybe that is a way of control cause even when my mom or my husband says, “stop pulling.” I don’t like that. I want to stop pulling when I choose to stop pulling.” (Participant 17)

“That is the point I get to when I am like, I just have to stop, like my fingers are numb, the tips are getting so numb, my nails are white - it is because of the constant pulling all the time. It is those little squiggly little ones, or the curly ones or the greys- now that I am getting older [laugh]. Those are the targets –and the short ones. The regrowth is also targeted, that is also what I pull as well.” (Participant 29)

“H’m, because as much as you want to stop and as much as you want to control it, it feels like you can’t, like you are just stuck in this place where that you can’t get out of no matter how hard you try or anything like that. And, I mean to see like the damage you are causing to yourself.” (Participant 31)

Subtheme 2: Onset

Age: Different ages of onset of hair-pulling were reported, ranging from early childhood to middle adulthood, with the average 14 years. Some participants understood their pulling behaviour as soothing behaviour learnt as a child.

Events or traumas linked to onset: Other participants viewed pulling as an action which provided relief during stressful periods or as a way of managing anxiety. Many reported their understanding of pulling to be a means of coping with a stressed atmosphere at home, school or work. Bullying, exposure to traumatic events, big changes like moving to another city or country, losing a loved one or post-operation recovery reportedly contributed to the onset of pulling in some cases. Drug and alcohol use were also viewed as causes linked to the origination of the behaviour.

People linked to onset: Some participants reported modelling someone else's pulling behaviour. Others heard stories of hair told by others which instigated the pulling. Two stories told during the interviews were that if you see an eyelash you should blow it away and make a wish, and that coarse hairs are dead hairs that should be pulled out.

Increased grooming: At times fiddling with hair when bored and looking for split ends can lead to pulling behaviour, as well as normal grooming that grows more intense. Some participants reported initially presenting with another body-focused behaviour, like nail biting and later started hair pulling. There were also reports of pulling after hair lice were discovered, and a lot of time spent feeling hair strands for nits.

Table 12 - Theme 1: Hair-pulling experience - Subtheme 2: Onset

"I think it was just a very, very stressful year. So, the one day, I saw someone doing it actually, at the study centre on campus and um... I just tried it out and it felt really nice. It was chunks and chunks of hair that I would pull out initially. I felt worse when I started doing it -more guilty, embarrassed then than I do now. I sort of made myself be okay with it. I should have probably stopped then, but I wasn't able to. It just helped me with the stress. That was a really stressful period, that was the only thing that I can link to it." (Participant 04)

"I think what started it was a traumatic childhood, my parents' divorce. I can link that time to when I started pulling." (Participant 07)

"Ek dink as ek deur 'n slegte of 'n, of 'n, nie noodwendig stresvolle situasie, maar deur 'n slegte tyd gaan of iets my lewe wat nie vir my lekker is nie, of emosioneel nie lekker voel nie, dan is dit vir my, was dit al vir my maklik gewees om klomp hare uit te trek." *[I think if I go through a difficult, or not necessarily stressful, but difficult time or something in my life isn't nice or emotionally I don't feel well, then it is easy for me to pull a lot of hair.]* (Participant 10)

"Ek was 13. H'm, in die koshuis in xxx en h'm, ja, 80km van my ma-hulle se plaas af en ons

het 'n onderwyser gehad wat vir my vasgedruk het en ek weet spesifiek dit is waar dit begin het.” *[I was 13. In the hostel in xxx and h'm yes, 80km from my parents' farm and we had a teacher that grabbed me, and I know specifically that's when it started.]* (Participant 15)

“People say its a nervous condition and I do worry that it's got – because I see my daughter biting her nails and that is the other thing I forgot to mention when I was younger, I first started biting my nails. Then when I was around about nineteen, the hair pulling started. So, I guess it was a little bit of a transference but now it is interchangeable.” (Participant 17)

“Ja en ek kan nie onthou presies wanneer ek dit begin pluk het nie, maar wat ek kan onthou... My blindederms is uitgehaal en onthou toe ek in die hospitaal gelê het. Elke oggend as die verpleegsters, [inasem] as hulle by my aankom en hulle kom maak skoon dan het daar bolle hare langs die bed gelê want ek het my hare begin uitpluk.” *[Yes, and I cannot remember exactly when I started pulling, but I can remember... My appendix was removed, and I remember when I lay in hospital. Every morning when the nurses came to me and tidied around the bed, there were bunches of hair next to the bed, because I started pulling my hair.]* (Participant 20)

“Wel, sover as wat ek kan onthou, dit het begin toe ek in my vroeë tienerjare was. En dis definitief, dit was definitief angstigheids gedrewe. En dit het nou ontwikkel in slegte gewoonte, dis definitief nie meer angstigheids nie. H'm, alhoewel as ek angstig is, sal ek miskien trek en so aan. Dis ook heelwat minder”. *[Well, as far as I can remember, it started when I was in my early teens. And it was definitely anxiety driven. And now it has developed into a bad habit, it definitely is not anxiety anymore. H'm, although when I am anxious, I might pull and so forth. It is also much less.]* (Participant 23)

“I started pulling my hair out about seven or eight years ago, living in Johannesburg, using drugs and in an abusive relationship. I am not really sure how it started, it just started, and I

couldn't stop. I had just managed to pull all my hair out and I had long hair down to here, and ya...um... I didn't understand it and it was difficult. People didn't understand what I was doing, they just thought I was going mad. I had never heard of it nor see other people do it, so I thought it was just me that did it." (Participant 26)

"I don't think that there was a major event that caused it, I think what happened was... I could be wrong, but I remember that I was standing outside my house and my cousin was there. My hair was wild, like, you couldn't tame it. It would be in a ponytail, but all these little baby hairs would be sticking up. We were talking, and my cousin leaned over to my hair and pulled out a strand. She was like, "this is a dead hair" - and dead hair does not sound good... Ya, like your hair must not be dead. So, I looked at it, felt it, and it was like that coarse hair. So, after that, I was like no, I need to get rid of all the dead hair. Then after that, it just became a habit. Then I think because the habit went on for so long, it was like a relief – I could do it when I became stressed. So, I think that is how it started." (Participant 36)

Subtheme 3: Immediate Impact of Pulling

Impact on hairstyle: A prominent impact of HPD, which related mostly to female participants, was hairstyles. These participants could not maintain the styles they would have chosen if bald patches and thinning hair were not a problem. In this population, hair was often pinned in a bun or ponytail to make it more difficult to pull and to cover patches. Some participants reflected that at times, hair might look neat but within an hour, so much damage can be done because of pulling. The bald patches and thinning hair also influenced the choice of a hairstylist. That is if participants got to a point when they trusted someone enough to work with their hair. The relationship with hairstylists will be discussed in more depth later in the chapter.

Impact on time: Another impact was the time pulling monopolises in a participant's daily schedule. Many participants reported that because of pulling, tasks may be delayed, interrupted or postponed. There were also reports of losing out on sleep because of night-time pulling.

Avoidance of activities: Most participants have at least one activity which they avoided because of the effects of pulling. They avoided swimming, spa treatments or other social activities where their bald patches might show or be discovered. One participant described not going to her graduation because she did not want to be capped and stand a chance of the bald spot being seen. Getting close to people was another activity some of the participants avoided. Letting people, like partners, friends, siblings and small children play with one's hair, was also taboo because of being found out or embarrassed. As mentioned above, many participants also avoided hairstylists.

Table 13 - Theme 1: Hair-pulling experience - Subtheme 3: Immediate impact of pulling

"Ek kan nie maak wat ek wil met my hare nie, so en dit is nogals sleg want h'm... ek sal graag sê nou maar my hare wil los dra. H'm..., ja, so dit het definitief 'n impak en ook die ding dat, h'm... dat ek basies sê nou maar soos wat ek nou-nou gesê het dat as jy sit, as ek sit en leer dan sal ek op die eerste blad beginne leer en dan sal ek beginne hare uittrek en dan sal ek net nooit verder kom nie en ek sal letterlik vir 'n halfuur net sit en glad nie leer nie en uittrek." *[I cannot do what I want with my hair, and it is awful because I would want to wear my hair loose. Yes, so it definitely has an impact and also, that I basically, as I said earlier, that if you sit, if I sit and study, then I will start on the first page and start pulling, and then I will never progress further and I will physically sit for half an hour and not study anything and pull.]* (Participant 02)

"Ek is bewus van die wind waai as ek my hare gepluk het. Dat dit nie oopwaai nie en ek sal ook nie dan swem nie. En as ek swem dan sal ek vinnig onder die water in, jy weet, so maak

dat die hare kan oorgaan...” *[I am aware of the wind when I’ve pulled my hair. That it doesn’t blow open and I will also not swim. And if I do swim, then I will quickly go under water, you know, so that the hair can go cover.]* (Participant 20)

Maar ek sien die grootste impak wat dit nou vir jou het, is dat dit neem tyd in beslag. *[But I see the largest impact that it has on me, is the time that it takes.]* (Participant 21)

It is very time-consuming in a sense that when you pull, so much time goes by that when you stop, it is almost half a day wasted. (Participant 29)

Ja, want die ding is, om dit weer op ’n punt te kry wat dit, jou hare en goed mooi lyk vat soveel langer as jy kan om ’n kwessie van ’n paar uur kan jy dit vernietig.” *[Yes, the thing is, to get to a point where your hair is healthy and looks good takes so much longer than the few hours it takes to destroy it.]* (Participant 35)

Subtheme 4: Insight

Participants presented with different levels of awareness of triggers, and insight and understanding of their hair-pulling. Some viewed the behaviour as purely habitual, while others made meaning of it in terms of self-soothing properties. Most participants argued that their pulling was reduced when actively engaged in any activity that asked for one’s full presence or participation. Similarly, at times when they were more relaxed (‘downtime’), the pulling manifested more readily. Another reflection by some participants was that they do not have to go anywhere or do anything to engage on the specific pulling behaviour – all they need is with them (e.g. hands and hair), which makes the behaviour all the more difficult to stop.

Table 14 - Theme 1: Hair-pulling experience - Subtheme 4: Insight

“So, when I am alone, that is when it gets me and when no one is around. I have also noticed when I am in a highly productive state I don't get that sort of urge. It is more when I am on that downward sort of path. When I am relaxed, then I feel the need to do it. It kind of conflicts with being productive. When I am reading something, that is when it happens.”
(Participant 04)

“Kyk, h'm, alles is net so gerieflik daar, jy weet, dis dis nie, sigarette moet jy gaan koop om te rook. Jy moet 'n sigaret optel en aansteek om te rook. Dieselfde met sjokolade of enige so iets. Dit is, buitendien, jy pla niemand eers nie, jy hoef nie eers op te staan nie, dis maar net, dit kan net aangaan.” [*Look, h'm, everything is just so conveniently there, you know, its not like cigarettes you have to go buy to smoke. You need to pick up a cigarette and light it to smoke. The same with chocolate or anything like that. And by the way, you don't bother anyone, you don't even have to get up, it is just, you can just continue.*] (Participant 8)

“I pull a lot more when I am stressed. Definitely from stress. Like I said to Christine before, there is still an impulse there, but I don't think it is nearly as strong as it was before. Now, it has almost moved to a habit. Because I do it every day. It is normal to come home and walk in the door and look in the mirror and see what is skew and get carried away.” (Participant 13)

“H'm, dis nie normale lewe, ja, dis maar net soos ek sê. Ek het nie ander tipes van ontlading regtig nie. Dis so maklik byderhand.” [*H'm, it is not a normal life, yes, but it is like I say. I don't really have other types of unpacking. This is so easily accessible.*] (Participant 39)

Theme 2: Emotions

The responses of participants regarding their emotional experiences relating to hair-pulling have been summarised under the following subthemes: 1) emotions prior to and/or leading to pulling, and 2) emotions during/after and/or because of pulling.

Subtheme 1: Emotions Prior to and/or Leading to Pulling

Multiple emotions were highlighted by participants as occurring prior to a pulling episode, of which the wording used by participants are provided below. They described feeling many negative emotions (e.g. feeling tense, frustrated, scared, out of control, anxious, 'blue mood', down, uncomfortable, annoyed, irritable, disappointed, in a dark place, embarrassed and emotional). These negative or challenging emotions experienced, often created a vicious cycle as described earlier in the chapter, that leads to more pulling behaviour. Neutral emotions (e.g. boredom, apathetic and self-conscious), as well as positive emotions (e.g. happy, relaxed and content) prior to pulling were also reported. However, expressed positive feelings linked to pulling were much less than negative emotions.

Table 15 - Theme 2: Emotional experience - Subtheme 1: Emotions prior to and / or leading to pulling

"As ek... tense voel, of ek moet 'n besluit maak. H'm..., dan sal ek hare uittrek, soos dit help vir my om my kop half in die regte rigting te kry vir die besluit, of die ander deel is ook as ek 'bored' is, soos sê nou maar ek sit en ek doen niks met my hande nie, dan sal ek nou byvoorbeeld begin hare uittrek." *[If I, feel tense, or I need to make a decision. H'm, then I will pull hair, like it helps me to get my head in the right direction to make a decision, or the other part is that when I am bored, like for example I sit, and I do nothing with my hands, then I will for example start and pull my hair.]* (Participant 02)

"Bang as ek dink aan die toekoms, want daar gaan 'n punt kom wat ek dit nie meer gaan onder beheer kan hê nie." *[Scared when I think of the future, because there will come a time*

<i>when I won't have it under control anymore.]</i> (Participant 02)
"And it does bring relief. I don't know if its... um, I wouldn't say anxiety but there is this build up and when I eventually pull out the hair, it's just like, calm. I need to get to that stage when I'm like, okay, it's fine." (Participant 04)
"I am just not in control of this thing I do. It bothers me that I am doing something that I am not controlling." (Participant 06)
"And I have told myself, I think I am an intelligent person, I am sane. I have told myself, you can stop this - but I can't! It is the one thing I can't, and I don't know why. And like I said, even when I am sitting watching tv and I tell myself, "Stop this now, you have been pulling for one hour!" It takes me less than ten minutes and I am pulling again." (Participant 07)
"H'm, stres en verveeldheid." [<i>H'm, stress and boredom.</i>] (Participant 20)

Subtheme 2: Emotions During/After and/or Because of Pulling

In general, participants reported guilt, shame, anger, frustration, disappointment and annoyance after a hair-pulling episode. Others reported pulling made them feel weak, irrespective of the fact that they saw themselves as strong and successful in multiple other areas of their lives. Many participants were more self-aware and self-critical post pulling, which lead to decreased confidence and feeling disheartened. They described feeling as though they failed, as though they were stuck in a destructive pattern and unable to manage the difficulty. A few participants reported previous suicidal ideation, which appeared to be closely related to the inability to control the urges and uncertainty about the pulling behaviour in the future.

Some participants said they would never pull again, that pulling was illogical and ridiculous – just to catch themselves yet again engaging in the behaviour. The shame of being caught in

the act of pulling, or patches and thinning hair being evident, also lead to the above described challenging emotions. In contradiction to the difficult emotions mentioned, there were minimal participants who reported short-lived relief, calmness and satisfaction after and during pulling.

Considering all above emotions, most participants reported a sense of being trapped within an emotional pulling cycle – finding it difficult to distinguish which came first, the emotion or the behaviour and that the one fed into the other, which made ending the cycle near impossible.

Table 16 - Theme 2: Emotional experience - Subtheme 2: Emotions during / after and / or because of pulling

“I felt weak personally because I am quite an in-control person. The process is really demoralising and then you get stuck thinking, - well that is it for life.” (Participant 01)
“die ‘guilt’ wat saamgaan, h’m..., kan partykeer nogals oorweldigend wees. So, ja, selfkritiek en so dink ek is erger as wat nodig is.” <i>[The guilt that goes with it, can at times be quite overwhelming. So yes, self-critique and I think it is worse than what is necessary.]</i> (Participant 03)
“Yeah so it causes anxiety, but it also takes away some of the anxiety. So, if I stop it, that impulse or that feeling that I get that I need to do it - what am I going to do with that? [laugh]. What else is going to happen? How do I let go of that?” (Participant 04)
“I am tired of this hey, it’s exhausting. I mean, I have been suicidal from this before, just not being able to control it and not knowing if I am ever going to be able to.” (Participant 26)
“It is very frustrating and also very satisfactory in a way.” (Participant 27)
“Ek dink dit is vir my die grootste goed is die ‘sense of failure’, die ‘shame’, h’m en die

‘anxiety’, die vrees.” *[I think the biggest thing is the sense of failure, the shame and the anxiety, the fear.]* (Participant 35)

Theme 3: Relationships

The responses of participants regarding the impact of hair-pulling on their relationships are summarised under the subthemes: 1) the role of the family of origin 2) family patterns of BFRBs 3) the role of community, friends and colleagues, 4) the role of partner/spouse, 5) the role of children, and 6) the role of the hairstylist.

Subtheme 1: Family of Origin

Family understanding: The family of origin was usually the first people who were aware of the pulling behaviour. Family members often viewed the pulling behaviour as a nasty habit that was within the participant’s control. Family members often commented and focused attention on the behaviour, which caused embarrassment. In general, at least one parent was supportive. Parents reportedly got fed up with the situation because they either did not understand the behaviour or were not empowered with the right tools to manage it empathically or effectively. Not being appropriately and fully informed of the condition played a significant role in the family dynamics. Shame about the pulling lead to non-disclosure of hair-loss causes, even when other special investigations were done for diagnostic purposes. Some participants, who pulled as children, reported that they were too ashamed to disclose pulling, even when consulting specialists. Some participants isolated themselves from extended family reunions, as they did not feel comfortable with more family members knowing about the pulling.

Family reaction: Whereas some family members acknowledge the behaviour, others just blatantly ignore the pulling and the consequences thereof. There were pros and cons to family members not mentioning the pulling. On the positive side, there was not a constant reminder, focus and criticism on the pulling, but on the negative side, no one was actively

helping them to address the behaviour and it is not really taken seriously. There was a general sense from participants that family members did the best they knew how in managing the behaviour. For most participants, as children, and even as adults, making their family understand a diagnosis that even they do not, was extremely challenging.

Efforts to assist stopping pulling: Some parents reportedly used punishment and negative reinforcement (i.e. slapping hand, scolding, taking away privileges) in an effort to end the behaviour. Participants were often unsuccessful in their attempts to avoid punishment because they struggled to not pull. Their family's management of HPD often left them feeling invalidated and ashamed. It seems that in many cases only when the pulling symptoms impacted daily life and lead to clearly visible bald patches, the family acknowledged a true difficulty.

Table 17 - Theme 3: Relationships - Subtheme 1: Family of Origin

"And my step mum was like, 'ah, you know if you were my child I would just slap you and tell you to get on with it.' Which pissed me off and I just lost it - I don't usually lose it (and I didn't shout) I was just like, 'look at my hair, look at my fucking hair, do you think that I would do this on purpose?' 'Do you think I would actively sit there and pull out my hair and look like an idiot.' And she was a bit like, 'whatever'." (Participant 01)

"En hier kom 'n dogtertjie en sy trek haar hare uit. Ek dink net nie my ma het noodwendig die 'tools' gehad om dit te hanteer soos wat iemand dit wou dalk sou hanteer nie. So, dit was, dit was nooit positief nie, maar ek kan haar nou nie blameer vir dit nie, want sy het nie van beter geweet nie. My pa, h'm, ek dink vir hom 'ignorance was bliss'. As hy nie aandag daaraan vestig nie gaan dit hom nie pla nie. So, h'm, ja, want ja... Selfde met my broer. Hy het my net nie aandag gegee nie, nie kommentaar gelewer nie, net niks gedoen of gesê nie. Dit het hom nie ge-'faze' nie." *[And here comes a little girl and she pulls her hair. I don't think my mom had the tools to deal with it like someone should have handled it. So, it was, it was*

never positive, but I cannot blame anyone for it, because she didn't know better. My dad, I think for him ignorance was bliss, if he didn't pay attention to it, it didn't bother him. So yes... The same with my brother. He didn't pay attention to it, did not comment on it, didn't do or say anything. Didn't faze him.] (Participant 03)

"But no one said, you know, you have a problem, let see why you are pulling your hair out. Even I didn't know why I was doing it. But they could have gotten someone else who could have told me I have a problem." (Participant 07)

"No... my mom was obviously confused. She didn't understand. People tell you, well I was told to just stop doing it. But it's not like I want to. It's frustrating. It put a lot of strain on our relationship because I don't understand it, why it's happening. I didn't know how to make my mom understand either. I only told her what it was years later. I think I was, like maybe sixteen - when I knew what the word for it was and when I realised that I had a condition. I think we both just didn't know." (Participant 13)

"Ya, there is an element of that, of why didn't she find out? It is like a bit of a weird thing to be doing. I don't know. If my daughter is doing something weird, maybe I would find out - ya, I probably would. But um, my mom is sort of a mind over matter person. I think the most annoying thing is her constantly telling me to stop and not realising that it is difficult to." (Participant 14)

"Soos, spesifiek nou my ouers omdat ek nou natuurlik meer met hulle te doen het, h'm en ja, om hulle, dat ek hulle teleurstel as ek dit nie kan oorkom nie en so aan. Jy weet..." [*Like, specifically like my parents because I have more to do with them, ja, around them, that I disappoint them if I cannot overcome this.*] (Participant 35)

Subtheme 2: Family Patterns of BFRBs

There were reports of other family members, siblings and/or parents, presenting with BFRBs (i.e. nail biting or skin picking). One participant reported her brother bit his nails and she pulled hair. They made each other aware when they engaged in these behaviours, as a way of helping to manage better. Finding humour in the situation with siblings who also have a BFRB was an ameliorating factor for some. When siblings controlled their BFRB better than the participant, it often left them feeling unable to manage as effectively. For some participants, the fact that others in their family pulled, came as a surprise – many had their suspicions, but others were completely unaware that they were not the only ones. Often participants kept quiet about their own behaviour, also to prevent others from feeling that copying them caused the pulling behaviour.

Table 18 - Theme 3: Relationships - Subtheme 2: Family patterns of BFRBs

<p>“I think my dad does, but it isn’t something that we have spoken about – just based on his appearance. I seem to remember that his mum, my gran also struggling with it, but it is obviously difficult to know because it wasn’t spoken about.”</p> <p>“my eldest has just started biting his nails. It isn’t noticeable on him, but I have noticed a couple of times, not to a serious extent and that was one of the reasons why I was trying to find something like your study. It is not as nice when you see it in your kids.” (Participant 27)</p>
<p>“My dad, he does a very similar thing. He pulls on his beard and his eyelashes.” (Participant 30)</p>
<p>My little brother, he still bites his nails a lot – it's quite funny. And we will help each other, I will be like: ‘stop biting your nails.’ And he will be like: ‘stop pulling your hair’.” (Participant 34)</p>
<p>“Ek het ’n suster wat dieselfde probleem het. En sy’t ’n lewenslange verwyd op, want sy sê</p>

ek het dit by haar gesien.” *[I have a sister that has the same problem, and she has lifelong self-resentment because she said I learnt to pull from her.]* (Participant 40)

Subtheme 3: The Role of Community, Friends and Colleagues

Disclosing HPD to the community: In general, pulling did not take place in situations where the person did not feel comfortable to engage in the behaviour. Even when no-one knew about the HPD, participants described always feeling different from other people, as though there was something wrong with them. Most participants knew only themselves who pulled and felt like they were the only people in the world facing this challenge. Meeting others with hair-pulling was an important part of the journey for some, as it countered the feeling of isolation. Some participants reported that study involvement normalised the behaviour by confiding in professionals who understood the diagnosis. They also reported that disclosure in the study made it more comfortable to disclose to others.

Understanding HPD: When they were more open about challenges faced, people often proposed solutions to stop the pulling. This usually frustrated most participants, as they have tried almost everything by the time they took others into their confidence. However, some participants reflected that it was important to keep in mind that they were only trying to help and that although disclosure took courage, it often leads to better support and understanding. According to some participants, HPD was not one of the classic OCD symptoms people recognised, so participants felt that others did not understand when they described hair-pulling. The fact that the behaviour may be labelled as freaky caused participants to not spontaneously disclose. Some felt that it was extremely difficult to explain a disorder that even they did not entirely grasp. Some participants noted that the longer people were involved in their lives, the better they understood the gravity of the situation. Informing and psycho-educating others, helped counter wrong perceptions of the disorder, so people could understand the seriousness of the condition.

Impact on community involvement: Some participants reflected that people spontaneously asking questions or making comments, highlighted that the pulling was creating challenges because cover-up practices was not as successful. Participants reported feeling nervous and shy when surrounded by people – in queues, after swimming, in lectures and restaurants, sitting under lights, in front of mirrors or having photos taken. They were constantly making sure that the damaged areas were covered. Often, they had a trusted person to warn if a bald spot showed or make-up rubbed off. Participants went to great lengths to hide the consequences of pulling. Those who pulled in school reported that it was difficult to cover-up because students could not wear make-up or certain hairstyles. They also reported challenges in partaking in activities like being a bridesmaid, because of make-up, hair styling or going to a spa with girlfriends. Some pullers shaved their heads so that pulling was impossible and were often asked whether they lost their hair due to illness or shaved it voluntarily. Other comments ranged from ‘looking cool’ to empathy that medically they must be unwell.

Table 19 - Theme 3: Relationships - Subtheme 3: The role of community, friends and colleagues

“What happens is people see you start to do it, at first they try and stop you. And it is also frustrating, cause your like, ‘listen, do you not think that I have tried everything.’ And they like, ‘what about this’.” (Participant 01)

“O, is jy, so jy is so bietjie mal, of, jy weet, jy hoort so bietjie in xxx psigiatryese hospitaal.’ En, maar daai persepsie wil ek verander, want ek dink ek funksioneer soos enige ander normale mens ten spyte van my, half vreemde persoonlikheid, h’m..., funksionering is soos enige ander mens, behalwe dat ek my hare trek. So, h’m..., ja, daai ding wil ek so half bietjie verander. Mense dink jy is heeltemal ’n sielkundige geval, dis glad nie so nie. So, ek doen wat enige ander mens ook doen en, h’m..., ja, so dis hoekom ek so half openlik daaroor is.”
[O, you are a little crazy or you belong in a psychiatric hospital. But that perception I want to

change, because I think I function like any other normal person in spite of my personality, hmmm, functioning is like any other person, except that I pull my hair. Hm ja, that thing I want to change a bit. People think that you are a complete psychological case. It is not like that at all. So, I do what any other person will do, yes that is why I am so kind of open about it.] (Participant 02)

“I never want to seem like I am a freak when I am with other people [laugh]. I am able to control it in that sense, its just always in the back of my mind.” (Participant 04)

“I don't think people understand how serious, or that it is a serious condition and that it is not easy to stop. I think when I was younger, maybe ten or fifteen, I would have liked to have told someone. But because I have lived with it for so long, I don't care. I reached that point that I don't care, and its better people don't know.” (Participant 07)

“Sê nou ek gaan swem in die middag, ek dra 'n keppie so dis nou fine. Nou kom ek uit die water uit en ek haal altyd my keppie uit en ek gaan droog af en dit is somtyds dat daar mense agter my of voor my sal wees en ek is bang om op te kom. So ek is konstant doen ek dit, konstant doen ek dit. H'm, ek dink my selfvertroue sal definitief beter gewees het as ek nie my hare uitgetrek het nie. H'm, as ek agter, ek kan so sê ek is miskien 'n bietjie langer as ander en so, maar as ek in 'n vergadering sit en daar is mense wat after my sit, ek is completely paranoid.” *[If I go swim in the afternoon, I wear my cap so that is fine. Now I come out of the water and take the cap off and dry myself and it is then when people are behind me or in front of me and I am scared to come up. So, I constantly do this. Hm I think my self-confidence will be better if I did not pull. If I am behind, I can say I am a little bit taller than others, but if I sit in a meeting and there are people behind me, I am completely paranoid.] (Participant 09)*

“A lot of other people don't understand what is going on. You just feel uncomfortable around

people. I am travelling by public transport, so you don't want people sitting behind you. When you get in the taxi you just want to sit in the back seat, so you are at least relaxed that no one is behind you. Even the hairstyle that I do, I have got to be sure that it is going to cover the back. The hairstylist understands the problem, so she helps me with how she styles my hair.” (Participant 11)

“No um... I have got good, close friends and I have never mentioned it. Since doing the study I have told one person that I am doing this study - the woman who looks after my child. I kind of felt that I could confide in her because I know she suffers from depression, so I felt she could relate to having a problem that you can't control.” (Participant 14)

“Ek wil dit baie graag verander, h'm, ja, dit voel vir my asof ek, want ek het nog nooit amper so iemand ontmoet nie, leer ken nie. So, ek wil, dit voel vir my asof ek die enigste een in die wêreld is en dat ek net weet daar is nog geen hulp vir dit nie.” *[I really want to change it. It feels as though I because I've never met or got to know anyone like this. So, I want to, it feels to me like I am the only one in the world and that there is no help for this.]* (Participant 15)

“Many people say to me: ‘If you didn't say anything or show me I wouldn't have known.’ But that is the point: the whole thing is to hide it.’ (Participant 25)

“Up till today, I go out with friends and stuff and friends tell me: ‘your hair is always perfect.’ But they don't know the real reason behind it. That is how it has been my whole life.” (Participant 29)

“But I mean for you to make a comment out of the blue, you don't know me. I don't know you and I don't presume to know what, what you're going through and what situation you're in. So, what gives you the right to comment on, on me and my life?” (Participant 31)

Subtheme 4: The Role of Partner/Spouse

In general, participants reflected that partners tried to be as supportive as they could, but seldom knew how to handle the hair-pulling effectively, which lead to frustration for both parties. Some participants thought the partner was unaware of the behaviour, just to be told that they did know, but was not sure how to address the situation. When aware, they were often the person depended upon to say if a patch showed or remind them when they engaged in pulling. Some participants were uncomfortable regarding physical contact with the pulling areas, which impacted physical intimacy. Most participants shared their diagnosis of HPD with partners but reported disclosing was challenging due to fear of judgment and rejection.

Table 20 - Theme 3: Relationships - Subtheme 4: The role of partner/spouse

"I think the fact that he told me to listen to the radio the other day, maybe he wanted me to listen and wanted that for me. When I told him that I would be part of the study, he was like: 'Okay good'! So, I suppose that was his weird way of showing support" (Participant 04)

"Ons het eendag gepraat toe sê ek vir hom ek doen iets wat ek nie van hou om te doen nie. Of ek het 'n gewoonte waarvan ek nie van hou nie. Toe sê hy vir my: 'Dis om jou hare uit te trek?' So, hoe weet jy? Toe sê hy: 'Nee, hy het dit agtergekom.' Ek was toe baie verbaas gewees." *[One day we spoke, and I said that there is something I do, which I don't like doing. Or I have a habit that I don't like. He asked me: 'Is it to pull your hair?' So how do you know? He said, no he has realised it. I was very surprised.]* (Participant 10)

"Maar, h'm, ek is baie bewus daarvan en en ek moet glad nie, my man moet ook nie aan my kop wil vat of aan my kop wil vryf of, ek sal onmiddellik, moenie, moenie raak aan my kop nie." *[But, hmmm, I am very aware of it and I must definitely not, my husband must also not touch my head or stroke my head, or I will immediately, "don't, don't touch my head".]*

(Participant 20)

“So, maar ek is baie verlig dat ek vir hom gesê het so ek hoef niks weg te steek nou nie...”

[So, but I am very relieved that I told him, so I don't have to hide anything anymore...]

(Participant 20)

“I don't let people touch my hair like I used to. I have always had the sort of same style. If my hair isn't tied up or in a sock bun, it is just pinned up or tied to the back. I do have a boyfriend now, for quite some time. He doesn't know about my condition. I thought I would tell him today, but I backed down so maybe I will tell him before the new year, I don't know.”

(Participant 29)

“My boyfriend is supportive as he can be. We have been together for eight years now. Like, I'm, I don't know. Look, he doesn't get frustrated or stuff with me. Sometimes he just would say: 'Okay, can you just like, can you just like stop now?' He is like: 'Just like look on the floor and look around the couch and see what it looks like.' (Participant 31)

Subtheme 5: The Role of Children

Some participants thought their children were not bothered by the hair pulling, while others grasped the dire impact the pulling had. In general, children took responsibility and scolded their parents when the behaviour occurred or commented on what their hair looked like to make them stop. The effects of pulling reportedly irritated them, made them worry and feel embarrassed amongst their friends. Adult children appeared to be more understanding and supportive. Other children were not aware of the pulling and participants wanted to keep them from seeing the behaviour, as to not model the pulling. When children themselves presented with hair-pulling behaviour or other BFRBs, it created anxiety for parents. Some participants hoped that taking part in the study would give them tools to better explain HPD and assist in managing their children's pulling behaviour.

Table 21 - Theme 3: Relationships - Subtheme 5: The role of children

<p>“Jy weet, ons sit eendag by die, by die netbal en ek sit onder op die pawiljoentjie want ek, my dogter sit bo [trek asem in van skok], sy kom na my toe sê: “Mamma, asseblief, loop net weg.” Want toe kyk sy so op hierdie kaalkop vas. [lag] En ek sit en cheer netbal en toe het dit seker nou oopgegaan...” <i>[You know, we sat at netball the one day and I sat under the pavilion, because I, my daughters sat above. She comes to me and says: “Mom, please just walk away.” Because she looked straight at the naked head. And I sat and cheered for the netball, and it must have uncovered.]</i> (Participant 20)</p>
<p>“There are times when you are tying your hair up or when my daughter said, “mom, you know what you look like from behind?” You become self-conscious.” (Participant 25)</p>
<p>“My eldest has just started biting his nails. It isn’t noticeable on him, but I have noticed a couple of times, not to a serious extent and that was one of the reasons why I was trying to find something like your study. It is not as nice when you see it in your kids.” (Participant 27)</p>
<p>“Ja, my kinders weet ek trek my hare uit. Hulle weet ek is hierso. H’m, dis nie eintlik ’n big deal nie. So, dis nou maar net wat ma doen.” <i>[Yes, my children, know that I pull my hair. They know that I am here. It is not really a big deal. It just is one of those things that mom does.]</i> (Participant 37)</p>

Subtheme 6: The Role of a Hairstylist

For the average person, going to the hairstylist is a treat, but most participants reported a visit to the hairstylist was more often than not, a dreadful experience. The difficulty was specifically linked to the fear that others would see the damage and ask questions. Even when participants disclosed to the hairstylist, the first time visiting a salon, the pulling would be the main topic of discussion all following appointments. For those that did not feel

comfortable to disclose where the damage came from, hairstylists often had their own theories. Some participants did not engage with the theories, just shrugged and said they also do not know what was going on. Others psycho-educated the hairstylist, so they can, in turn, help their clients and provide them with the necessary information on HPD or BFRBs. Participants reported never going to a hairstylist close to where they lived or to someone their friends recommended. There was such a yearning amongst female participants to feel feminine, pampered and beautiful like they imagine others without HPD feel. Some of the participants had not been to the hairstylist in ages – they rather asked a trusted family member or friend to cut their hair. Others cut their hair themselves. However, when a trusting hairstylist relationship was established, this person seemed to become a true confidant, and often recommended styles that made hiding pulling damage easier.

Table 22 - Theme 3: Relationships - Subtheme 6: The role of a hairstylist

“Now when you are at the hairdresser everyone else sees, it’s not just the hairdresser. Everyone else at the salon will see that your hair is not as nice as other ladies’ hair. Then they ask, ‘Oh, what happened?’ I actually had the courage to tell one hairdresser, ‘You know what, I actually have a problem, I pull my hair out.’ But then every time that I went to her she said, ‘so do you still pull?’, ‘Are you still pulling?’ She would say it loudly so that other people would hear so for me that was... I didn’t mind telling her, but I didn’t want other people to know.” (Participant 07)

“Even the hairstyle that I do, I have got to be sure that it is going to cover the back. The hairstylist understands the problem, so she helps me with how she styles my hair.” (Participant 11)

“I don’t discuss it with my hairdresser, I have never told my hairdresser. She every now and again comes up with ideas of what it might be, and I just say, ya well...” (Participant 12)

“So, I just let them know, ‘So, look when you start working on my hair, you will find a bald patch,’ and ‘Yes, I pull my hair.’ Sometimes I will explain if they are interested in knowing why it’s like that and other times, I just won’t bother.” (Participant 17)

“In terms of self-esteem, especially growing up as a lady, I never look forward to hair salons, dying my hair or getting a new hairstyle because I can’t. Those are the things I cannot do. Dying my hair is painful cause I have open little follicles in my head and it burns. I think I have been suffering with trich since I was 11 or 13. So it is a long time and the hair salon that I have been visiting is the same and have had the same hairdresser who was the first hairdresser that dyed and cut my hair. To know that they are changing in such a way that they are becoming accommodating to people like me, is really amazing.” (Participant 29)

“That is why I had to give my hairdresser the Facebook page reference and the name of the condition. We need to make them aware.” (Participant 29)

Theme 4: Interventions

The responses of participants regarding their experience of interventions for HPD are summarised in the following section under the subthemes: 1) self-help attempts 2) medication and diagnosis 3) psychotherapy and 4) ineffective outcomes.

Subtheme 1: Self-help Attempts

Finding information: One of the most reported avenues participants followed to get to the bottom of the hair-pulling and find ways to address it, was the internet. In general, participants felt relieved to discover that pulling was a diagnosable condition called HPD. However, when investigating treatment options, they noted various resources in other countries but very limited resources in South Africa. On further research, most participants

reflected disappointment when realising there was no treatment with a definite positive long-term outcome.

Non-pulling strategies: Some participants argued that they could not just stop pulling but needed another behaviour or other activities to replace it. They reportedly tried various strategies – from willpower, prayer, gloves, others pinching, slapping or scolding. Others tried playing with clay or an object with different textures (fidgety toys), or a stress ball. Others wore a cap/beanie/scarf, wrote motivational letters, placed motivational sticky notes, sat on their hands, held an object, did not go to the bathroom alone, rubbed olive oil into their scalp, put Vaseline on their hair or wore an elastic band to pull when urge arises or put plasters on fingers. Some also reported that they tried to think more positive thoughts, be more conscious of pulling and more mindful of being in situations that might lead to pulling. Keeping busy helped – they worked in the garden, cleaned or knitted.

Hair-styling strategies: Styling hair also helped to an extent, because of time and often money invested in making sure bald patches were covered. Some participants added hair extensions, used make-up and / or expensive shampoos, shaved or kept hair very short. There was ambivalence between keeping hair long enough to cover patches and keeping it short enough to not be able to pull comfortably. Participants who could cover damage, often reflected that they were lucky, because they know that there were people whose HPD was too severe to cover or hide.

Table 23 - Theme 4: Interventions - Subtheme 1: Self-help attempts

“So, I am lucky I have always managed to hide it somehow.” (Participant 01)

“Dinge soos om my hande besig te hou met iets soos speel met ’n stukkie klei, of, h’m....., wat ons ook gevind het, teksture werk nou vir my. So ek maak byvoorbeeld, op daai stadium het ek baie boek gelees, so ek maak ’n boekmerk met verskillende teksture daarop of so.”
[Things like to keep my hands busy with something like a piece of clay, or what we also

found, was that textures work for me. For example, at that stage I read a lot, so my bookmark would have different textures on it] (Participant 02)

“Keeping my hands busy helps. I will try do something with one hand, so my other hand is free.” (Participant 03)

“One of them was set yourself little goals, like, ‘I am not going to touch my hair for a day.’ When I realised I couldn’t through a day I realised this has gone beyond a habit. That was when I got a little bit concerned and just frustrated, ya.” (Participant 06)

“En ek het my hare al baie kort gesny ook en dan het ek ook opgehou vir ’n ruk.” *[I have cut my hair very short as well, and then stopped for a while.]* (Participant 10)

Subtheme 2: Medication and Diagnosis

Diagnostic clarity: Almost all participants reported that they had no formal diagnosis initially but read about the behaviour in various sources and drew their own conclusions. Failing to disclose symptoms, posed a great challenge for clinicians regarding accurate diagnosis and appropriate management. One participant reported that she was diagnosed with HPD by a dermatologist but did not want to acknowledge that she presented with pulling behaviour. Another doctor prescribed prenatal vitamins for a diagnosis of alopecia because the participant was too embarrassed to talk about pulling. Participants reported that it was essential to be truthful about pulling behaviour, to receive the correct diagnosis as soon as possible. However, receiving a diagnosis rarely was an indication that a participant was committed to stop pulling completely.

Medication: Some participants did not want to take medication and reported that it felt like a weakness being unable to manage pulling without pills. When the diagnosis was clear, the first line of treatment was usually anti-depressant medication. However, the general

participant feedback was that they did not want to take medication unless it was absolutely necessary. Some participants have tried various medications, reportedly with poor effect. They felt frustrated that there were so much trial and error in prescription and that treating HPD was not more straightforward.

Table 24 - Theme 4: Interventions - Subtheme 2: Medication and diagnosis

<p>“Die medikasie het definitief ’n invloed op my gemoedstoestand, maar het geen invloed op die trich nie.” <i>[The medication definitely had an influence on my mood state, but no influence on the HPD.]</i> (Participant 03)</p>
<p>“I searched online and there wasn't much at all. In South Africa, there wasn't much.” (Participant 07)</p>
<p>“Nou dis wel ’n verligting om te weet daar is ’n naam daarvoor.” <i>[Well, it is a relieve to know that there is a name for it.]</i> (Participant 10)</p>
<p>“By the time I had matriculated my hair was much worse than it is now. Sufficiently bad for my parents to be called in by the head principal. That's when I saw a dermatologist and he diagnosed it. I denied it. I said, ‘No, I am not doing that.’ My parents believed me. They accepted it at a level. So, it was correctly diagnosed then. I remember it vividly.” (Participant 12)</p>
<p>“Maar ek sal nie eintlik baie graag wil medikasie wou gebruik.” <i>[But I don't really want to use medication.]</i> (Participant 23)</p>

Subtheme 3: Psychotherapy

Many participants grew up in an era when mental health issues were stigmatized, not talked about and seeing a psychologist was frowned upon. These participants, in general, only sought therapeutic input when they reached adulthood. For some of the younger

participants, seeing a therapist was part of the treatment during childhood. Therapeutic intervention reported, ranged from psychodynamic psychotherapy to explore the root of the difficulty, to behavioural principles and CBT based modalities. Hypnotherapy helped some participants for a short period. Eye Movement Desensitisation and Reprocessing (EMDR) therapy was also a modality mentioned, but reportedly without long-term effect. One participant also received scalp stimulation from her hairstylist.

Table 25 - Theme 4: Interventions - Subtheme 3: Psychotherapy

"I can't identify the triggers. And I have been speaking to psychologists about it. The first time speaking about it, it was like, oh it's a habit and we need to break the habit. Cause I told her, I don't want to do any, like, deep soul searching [laugh]. But we still couldn't figure out the triggers. The next time I did hypnosis they were like, it's related to anxiety. Then with the EMDR, it was related to the fact that I was bullied when I was younger. So, it was PTSD related. So, you have had this trauma and if you are back in that situation or any such triggers... and I was like, that makes sense actually because the triggers are so subtle because of the way trauma works in your brain and you would never be able to identify it. It could just be a feeling or you know... so um, I went for another EMDR last year and I stopped for 3 months and then I went to England. Then I was in a situation which was very much like being bullied again and I started again. So I am still now leaning towards, if I am in a situation which there are certain set of things which are reminiscent to when I was bullied, where I was on my own, in a new country and people were being mean to me and I didn't understand why nor could I get away from it and I had to suck it up. Basically, it is very hard to identify triggers. Because every time I started pulling I have been in a different country or a different situation. There isn't one thing that I can say, 'Oh, that is always there.' Sometimes I have been totally happy and chilled and whatever, and I just start pulling. That is frustrating cause I can't treat it. And I want to be proactive about it but if you don't know what to treat, then you can't treat it." (Participant 01)

“Alhoewel ons het daaroor gepraat en so, maar dit was meer net oor die management daarvan.” *[Although we have spoken about it, it was more about the management thereof.]*
(Participant 02)

“Ek het h’m..., einde laas jaar vir ’n paar sessies gegaan vir ‘cognitive behaviour therapy’ en in die tyd wat ek in die terapie was, het dit definitief afgeneem, maar kort daarna was dit maar net weer wat dit voorheen was voor die terapie” *[I had a few sessions of CBT last year, and in the time, I was in therapy it definitely decreased. But shortly thereafter it was the same as it was before therapy.]* (Participant 03)

Subtheme 4: Ineffective Outcomes

Most participants tried various interventions to stop pulling and proactively made plans to access relevant resources. However, these treatments did not appear to provide long-term solutions. The disappointment of searching for an alternative after a treatment was not successful and led to frustration. Some participants reflected that not understanding what the root of the problem was, made it difficult to search for appropriate treatment options. Others felt that they would try different treatments for however long it takes.

Table 26 - Theme 4: Interventions - Subtheme 4: Ineffective outcomes

“What is annoying is that each time you go you think you have found the root cause, but then it doesn't work?” (Participant 01)

“Dis saam met jou, so dis nie asof jy nie dit kop nie. H’m en ek dink dit is dalk wat moeiliker maak en meer van ’n uitdaging maak as die ophou rook.” *[It is with you, so it is not as though you don't ‘get it’. I think that is what makes it more difficult than stop smoking.]* (Participant 08)

Theme 5: Self

The responses of participants regarding their own self-reflections are summarised in the following section under the subthemes: 1) beliefs 2) the impact of not being aware of what the behaviour is 3) other BFRBs or OCD-like behaviours, and 4) how would life be without HPD.

Subtheme 1: Beliefs

Participants had numerous beliefs surrounding pulling, which were often reflective of their personal characteristics. For example, some had the beliefs that they should be able to stop pulling, control their behaviour, and were weak for being unable to do so.

Many participants reflected that they did not have as much control as they thought they had, and at times felt consumed by the behaviour. A participant, who was very controlled and structured in other life areas, theorised that pulling was possibly her way of letting go of control from time to time. Participants who started pulling at an older age deemed themselves lucky to have skipped the difficulties that may arise when pulling as a learner at school. A busy lifestyle often kept participants from pulling and they were grateful to not have time to pull.

Participants frequently rationalised the behaviour and reasoned that pulling could have been another, worse habit like smoking or using substances. One big concern was the amount of time pulling took. There were 2 considerations linked to stopping: 1) participants wanted to stop the behaviour because of all the negative consequences, 2) on the other hand, they still wanted the feeling that accompanied the pulling. Self-blame often ran deep. One participant visualised hammering a nail in a tree every time she pulled, and when she stopped the behaviour, she removed the nails and saw the damage. The white lies told to hide the pulling, also created feelings of guilt and shame for participants.

Table 27 - Theme 5: Self-reflection - Subtheme 4: Beliefs

<p>"I found it very frustrating because I am not a very emotional person and I also felt very much like - you should be able to stop doing this. That process is really demoralising and then you get stuck thinking, 'well that is it for life. It is never going to go, I am never going to be able to fix it.' " (Participant 01)</p>
<p>"Especially, like, I am the type of person that likes to think of myself as a capable person. If I want to do something, I will do it. I will train myself to do it and I will do it. The fact that I can't do this one thing that is so personal to me in my life, is so frustrating." (Participant 01)</p>
<p>"Trich sou ek sê is nie die moeilikste toestand om mee saam te leef nie, as ek dit moet vergelyk met ander toestande wat ek al van gehoor het of gesien het, of wat ookal, dink ek dis okay, maar ek dink definitief nie dit is die maklikste toestand om mee te lewe nie." <i>[I would not say that HPD is the most difficult disorder to live with. If I have to compare it to other disorders that I have heard of or seen, I think it is okay, but I also do not think that it is the easiest disorder to live with.]</i> (Participant 03)</p>
<p>"So, I think that is the main thing that is affected really - not badly but I notice it. I am so focused on pulling out this hair properly, so I don't leave one piece behind on my skull. I end up not focusing on what I am doing so I am studying, but not really studying. So, it's a waste of my time." (Participant 04)</p>
<p>"I just don't like that I do that, and I just don't like that I can't stop it. That bothers me. Ya...um... I am a slightly controlling person, so I like to have control over things in my life. So, it frustrates me that I cannot control this habit." (Participant 06)</p>
<p>"I think I would have been more confident. Because I had beautiful hair. I have lost confidence. I think I felt, not ashamed, I felt that I am not um... there is something wrong with</p>

me. I feel like I am not like other people. When I see the girls my age, I feel like I am not a normal person, something is wrong with me.” (Participant 07)

“I have a sneaky suspicion that if I was a stay at home mom and didn't have much to do, having more free time on my hands, I suspect my hair pulling would be much worse than what it is. I think it's my lifestyle that has in a way, saved me. As much as people say, ‘Slow down, take time to relax, take time for yourself.’ For me, I think that would actually be bad because of the hair pulling.” (Participant 17)

“I can't imagine ever having hair again, I really don't know. I want it, I mean, I am so tired of trying to hide it.” (Participant 26)

“Time-consuming in a way could be hours. It's very emotional and makes you feel very shy. It is also very, sort of new, new in a sense that you always finding a new ‘nothing’, a new bald spot. Like I said, it is very frustrating in a sense that you have an image of yourself, how you want to be or look, but it just never gets there.” (Participant 29)

“So, for trich. Um... I wouldn't say why me, because why not me? If I look at other girls with beautiful long hair, and I ask: ‘why me?’ Why not me? Because something has to happen to me because I need to be a messenger. Not too long ago, I sat in a narcotics anonymous meeting, with a family member as a visitor. Someone mentioned, ‘why him?’ Why did he have to be involved in crime and addicted to drugs and stuff like that? It made me think about myself, ‘why me?’ And I thought, but why not me? So, I think trichotillomania has impacted my life greatly like on a scale of 1-10, I would say 10. In terms of self-esteem, especially growing up as a lady.” (Participant 29)

“Oe, you know you go through these like days where you can, where you can like feel like you can deal with it and then there's another day when you just go into, almost like a like a

dark place, h'm, because you feel like so disappointed in yourself that you like ask yourself a question like: "Really like why can't do just like ruk jouself reg *[come right.]?*" (Participant 31)

"It has an effect on my confidence, my self-esteem, how I think of myself and how I present myself. I used to be a really outgoing person and now I am just like: 'It's okay, I will just sit here, in the shadows'." (Participant 36)

"Ja, so ek dink nie ek verstaan dit goed nie dit is vir my moeilik en, uhm, en omdat ek natuurlik ook baie skaam is daaroor. Dis iets, 'n gedeelte as gevolg van my professie, maar ook net 'n gedeelte om dit 'n beheer ding is. So ek dink dit is vir myself omdat ek moet baie leuens moet vertel soms daaroor, spesifiek wanneer ek haarkapper toe gaan en my hare laat sny. Omdat 'n groot gedeelte hier onder korter is, natuurlik want dit is waar ek dit doen. En dan vra mos altyd, maar voor hulle vra het ek al 'n storie wat semi die waarheid is, maar semi glad nie. Dis nie vir my lekker nie." *[Yes, so I don't think I understand it very well, it is difficult for me, also because I am very shy about it. It is, partly because of my profession, but also just partly because it is a control thing. So, I think it is for myself because I have to tell a lot of lies about it, specifically when I go to hairstylists for a haircut. Because a big part of my hair underneath is shorter, because that is where I pull. And then always before they ask, I have a story ready that is semi-true, semi-untrue. I do not like that.]* (Participant 41)

Subtheme 2: The Impact of Being Unaware of what the Behaviour is

Most participants reported being uncertain of a diagnosis or knowing what the behaviour is, which they found unsettling. Many thought that the pulling was just a bad habit, and never considered hair-pulling to be a diagnosable disorder. For many it was a lightbulb moment when they realised what they were doing was symptomatic of an illness. This realisation meant that they were not alone in their experience or the only one in the world with this difficulty, as many described. Participants reported that because they did not know what they

were dealing with, it was so much more difficult to find the primary cause and solve the problem.

Table 28 - Theme 5: Self-reflection - Subtheme 2: Impact of being unaware of what the behaviour is

“But no one said, you know, you have a problem, let see why you are pulling your hair out. Even I didn't know why I was doing it. But they could have got someone else who could have told me, I have a problem. I came across an article, I think in my teens in a magazine that related to hair pulling or something or the other. I think that is when I had a light bulb moment. I thought you know I have a problem, there is nothing wrong with me - I have a problem and there is such a problem. But there was no one I could speak to about it.”
(Participant 07)

“Fantasies en nou is ek gediagnoseer. Nou voel ek baie beter, want ek het actually 'n afwyking. Dit is nie h'm, dis nie iets wat ek alleen mee lewe wat ek dink net ek het nie. Nou dis wel 'n verligting om te weet daar is 'n naam daarvoor.” *[Fantastic and now I am diagnosed. Now I feel better because I actually have a disorder. It is not something that I have to live with on mine own, just me anymore. It is a relief to know there is a name for it.]*
(Participant 10)

“It was relieving, to be honest. I thought I was the only person in the world. I haven't personally met anyone else with the same thing. After you research, you realise there is no cure, so it wasn't really helpful.” (Participant 13)

“Voel vir my asof ek die enigste een in die wêreld is en dat ek net weet daar is nog geen hulp vir dit nie.” *[To me it feels as though I am the only person in the world and that there is no assistance for it yet.]* (Participant 16)

“I have had it for as long as I can remember but I have recently started researching more

about why I was doing it, only then did I realize that it was a condition not just something that I did for no reason. I didn't realize that um... that other people might do the same thing."
(Participant 27)

"I think I understand it better now, now that I am elder and can access the Internet. I now know what I have and how it feels. I know exactly what to look for. When I read this girl's blog, every single thing - almost everything I can relate to. Yes, our life circumstance is different, and we come from two totally different places and stuff like that, but we can both relate to this in our lives. Almost everything that she writes is relatable like her fingers hurting - I never knew that anyone else's did." (Participant 29)

Subtheme 3: Other BFRB or OCD-like Acts

A few participants reflected on other odd behaviours they exhibited in the past or still present with currently. These behaviours included writing in the air, being very neat and putting objects in a straight line, stepping on blocks in a certain pattern, stirring coffee a certain amount of times, hanging towels in a specific way, biting fingernails, being extremely detail orientated, skin-picking, removing imperfections (like zits), and scratching or stroking a small blanket. When the topic arose during the interviews, self-harm type behaviour was denied.

Table 29 - Theme 5: Self-reflection - Subtheme 3: Other BFRB or OCD-like acts

"And then that (other odd behaviours) stopped and then I can't remember what happened in between. And then the hair pulling started four years ago and I haven't been able to stop since." (Participant 04)

"I don't really know where this hair pulling comes from or whether it has anything to do with a nervous disorder. I am a little bit obsessive compulsive, but not much. It certainly isn't noticeable, but I am noted at work for being very detail orientated, for getting things done

and for pursuing something until I get it.” (Participant 17)

“Toe ek ’n tiener was, was dit verskriklik baie en weer het dit met die procrastination. So ek sal eerder sit en as ek ’n puisie sien of iets sien soos enge imperfection sien sal ek so daaraan gaan krap en soos, so dit gaan ook oor imperfection. Dit gaan nie noodwendig oor soos ek gaan soek vir goeters, dis nie soos en dan ook op ander mense.” *[When I was a teenager, I was horrible, and it had a lot to do with procrastination. I would rather sit and if I see a zit or anything like an imperfection, I would scratch it. So, it is about the imperfection. I do not necessarily go looking for things, not like that, but then also on other people.]* (Participant 38)

“Het naels gebyt toe ek jonk was en ek het baie gekrap op ’n stadium en ek het so half my nek gekrap. En uhm, en ek het met my hare gespeel altyd, altyd dit so in die ronde gedraai. En ek het onthou op ’n stadium het ek toe begin om die, uhm, die na die ‘dead ends’ te kyk.” *[Bit my nails when I was young, and I scratched a lot at a stage, also scratched my neck. I played with my hair, always twirled it. And I remember at a stage starting to look at the dead ends.]* (Participant 41)

Subtheme 4: Life without HPD

Some participants reported that they saw themselves just as functional as the average person, but with an added challenge of HPD. The impact on confidence, self-image and self-esteem were highlighted clearly while talking to participants. They felt that these factors would most definitely improve if they did not have HPD. Another factor that played a role in their frustration, was that pulling took up so much time. They felt there would be more time available to engage in other activities. One participant reported that her inward personality would match her outward personality and that she would be more confident and bubbly. Another said that she would be less irritable with herself but would probably still

procrastinate in other ways. Another big difference highlighted, was that people would not ask uncomfortable questions. They would be able to join activities without worrying about hair or make-up. Participants reflected that there would be no bald patches, and thus would not constantly wonder what people think or whether they can see the damage. The thought of life without HPD was described as very freeing and literally ‘letting your hair down’.

On the flip-side, some participants reported that they found comfort in the behaviour and were worried about what they would have to do for that soothing experience without pulling. Most participants have never had the experience of not pulling or could not remember such a time.

Table 30 - Theme 5: Self-reflection - Subtheme 4: Life without HPD

“Self-confidence and esteem, obviously they are linked. But you can be confident but have lower self-esteem. To me, confidence is how you actually present yourself towards a person, not really how you feel about yourself. Because my esteem isn't based on my looks and that doesn't really bother me that much, so the hair pulling doesn't really make a difference to that. But how I feel about myself, the way I look, and my confidence would be improved if I didn't have so many bald patches or if it was something that I have to hide.” (Participant 01)

“Niemand sal meer vir my daai vra nie, so ek sal nie meer daai vrae hoef te antwoord nie. H'm..., as ek iets kry om dit soortvan te 'replace' dan sal dit daai 'satisfaction' deel daarvan, want, want ek dink ek gaan die 'urge' hê om dit te doen. Dit gaan net 'n ding wees om dit te beheer. Maar h'm..., ek sal iets moet kry om dit te 'replace' dan, want ek gaan nog steeds daai 'urge' hê.” *[Nobody will ask me those questions and then I would not have to answer them. If I can get something to replace then the satisfaction part of it because I think I will have the urge to do it. It is just going to be a thing to control. But I will have to get something to replace it because I will still have that urge.]* (Participant 02)

“I am scared that if I do stop pulling my hair, I won't know how to handle it because I have

never had to handle it.” (Participant 12)

“My confidence would boost. I feel like, well it is ugly. It's also very draining. You don't realise that an hour or an hour and a half had gone by that you have spent standing in front of a mirror. It's gross in a way. You are also embarrassed by yourself or ashamed. Your self-esteem lowers and then the next day you just don't want to go to work and like, it's hard. My confidence would definitely boost a lot, I am sure. I would have less time standing in front of a mirror.” (Participant 13)

“Ek dink dit sal bevrydend wees. Dit sal, ek dink ek is, jis ek is in beheer van dit. Maar nou is dit in beheer van my.” *[I think it will be freeing. It will, I think I, I am in control of it. But now it is in control of me.]* (Participant 16)

“Weet jy, ek dink nie die lewe sou verskriklik anders gewees het as dit nie, dis net 'n stupid ding om te doen.” *[Do you know, I don't think my life would be so incredibly different, it is just a stupid thing to do.]* (Participant 23)

“I actually don't know. It would probably be the same - I would just have hair. I would probably have a lot more time on my hands; it wouldn't take me so long to get ready. Yes, actually my life would actually be different. I would spend a lot less on hairspray, hair pins, and hair accessories. I would just be able to enjoy it without so much hassle. I am very sort of, perfectionistic; I have perfectionistic ways about me and I think it is because of my trich.” (Participant 29)

“Time is the most important factor. I would also be able to enjoy life more, a lot more actually because I get very anxious just when people stand behind me in a queue. I cannot be relaxed at all. What I have been doing, I have been wearing a cap, but I cannot wear a cap all the time, my head sweats, and I hate 'sweaty stuff' like that.” (Participant 29)

Contact 2: Immediate Post-Intervention Session - Experience of Training

30 interviews were included from the immediate post-intervention session (second contact or T2), thus only including the participants who did not default. During the second interview with the participant the questions from which the interview flowed were as follow:

“Tell me about your experience of being part of the study?” and “Tell me about your experience with the cognitive training?”

The 2 main themes identified are:

- Theme 1: Training experience
- Theme 2: Training effects

Each of the main themes is divided into subthemes and supporting quotations from interviews are provided.

Theme 1: Training Experience

The responses of participants regarding their training experience are summarised in the following section under the subthemes: 1) training commitment, and 2) subjective training experience.

Subtheme 1: Training Commitment

In general, participants who progressed to the second interview, showed commitment to training, reportedly not wanting to disappoint researchers or themselves by defaulting the program. They also reported that they wanted to contribute to the study, the best they possibly could. However, most participants stated that as time progressed, it was more difficult to stay committed to the training. The novelty wore off and training felt more like a task and less like playing a computer game. Many participants noted partaking in the study for the greater good of the population struggling with HPD and thus completed the program even though they felt that it was too time-consuming.

Table 31 - Theme 1: Training experience - Subtheme 1: Training commitment

<p>“So, maar, ja, dis, partykeer moeilik om dit vol te hou, maar ek het belowe.” <i>[So, but, yes, sometimes it was difficult to keep on training, but I made a promise.]</i> (Participant 02)</p>
<p>“Dit was lekker h’m, aan die begin was dit bietjie meer interessant en dan dan raak dit moeiliker en dan raak dit meer frustrerend, maar ‘overall’ was dit was dit ‘alright’. H’m, dit het ’n bietjie dissipline gevat om dit elke keer te doen.” <i>[It was nice, at the start it was a little bit more interesting, then it becomes more difficult and then it gets frustrating, but overall it was alright. It took a bit of discipline to do it every time.]</i> (Participant 33)</p>
<p>“So dit het vir my gevoel h’m, asof daar ’n ‘investment’ is van my kant en julle kant om sê maar iets te doen of die groter doel of hoe dit ook al is en dit maak dat ’n mens dan meer emosioneel ‘obviously invest’. Dis ’n mens se tyd, so h’m, daai is ’n outomatiese ‘investment’ wat mens maak en ek dink dit laat jou dan bietjie meer irriteer, ’n bietjie meer bewus raak van wat is die ‘triggers’, h’m waar, watse tipe, of tipiese patrone, h’m, ja, so ek dink die bewustheid, of bewusmaking daarvan vir myself was vir my goed. H’m en ja en dan is dit net, ek is baie nuuskierig om te weet waarom en wat dit nou eintlik is.” <i>[So, it felt to me as though there is an investment from my side and your side to invest something. It is a person’s time, that automatic investment one makes, and I think it leaves you a bit more irritated, makes you more aware of triggers, what type, or patterns. Yes, so I think the awareness, of creating awareness thereof for myself was good for me. Yes, and I am curious to know why and what it really is.]</i> (Participant 41)</p>

Subtheme 2: Subjective Training Experience

Many participants described the training as an interesting experience and an activity that could make a real difference when done regularly. Instructions were reported as easy enough to follow. Challenges mentioned by some participants included switching off from

daily life to focus specifically on training. For other participants, it was a challenge to disconnect from social media for the 50 minutes a day. Before training, some participants described being nervous that they would pull hair while working on the computer, but this was not reported as an issue. Many participants reported that keeping to the training schedule was more challenging than initially thought. They often attributed the challenge to the duration of training sessions, tasks' difficulty increasing, poor internet connection, and game repetition leading to boredom. Others reported feeling rushed by the timing meter on the screen. The participants who completed the true intervention were positive about the option of following their training progress.

In general, participants who completed the training were proud of themselves for committing to the process and following through on the commitment. Training almost every day led to a certain level of consciousness and awareness of pulling. Participants reported that they felt good partaking in research that could assist in possible advances in treatment and knowledge about the condition. Some participants recommended that future trainees should plan carefully before the training starts - when to schedule the sessions and to train in a quiet undisturbed environment, as recommended by researchers at the onset of training.

Participants could not compare cognitive training to the control condition, as they were blinded to their group inclusion. However, in general the feedback from the groups differed concerning emotion experienced when in front of the computer. The cognitive training seemed to create more frustration when failing a subtest, whereas the control condition, puzzle building, was experienced as more relaxing.

Table 32 - Theme 1: Training experience - Subtheme 2: Subjective training experience

"So, ja, dit was, ek sou sê dit was nogals 'n plus punt en h'm, ja verder, alles het 'smooth' gehardloop en ekke dink dit is 'actually' iets wat ek, ek ken nie rêrig die program nie, maar as mens dit, ek dink soos jou hele lewe lank deur gereeld doen dan gaan dit 'n groot verskil maak 'actually'." [So yes, it was a plus point and everything went smoothly, and I think it is

actually something that I, I don't know the program, but if one can, I think do often through your whole life, then it can actually make a big difference.] (Participant 02)

“Dis vir my bitter soet dat dit nou verby is. Dit was definitief meer van 'n uitdaging as wat ek gedink het.” *[It is bitter sweet that it is over now. It was definitely more of a challenge than I anticipated.]* (Participant 03)

“Like I told you, in the beginning, I really enjoyed the training part of these exercises. I am very interested to see what the long-term outcomes are going to be. I was quite keen to be part of the study. I quite enjoyed it, it wasn't a mission to be a part of.” (Participant 04)

“It was challenging, but it was quite nice to actually slowly seeing that there was some improvement. But ja, h'm, the time, it was just, it took a while. I found h'm, I would have liked it to be a little bit shorter.” (Participant 06)

“I looked forward to, and also just, I mean you, you don't know if nothing is going to, or if something is going to happen. But you, well, I personally just like wanted to do it properly so that I could see for like you can't, you know if you're not going to do it properly then you might just as well not do it.” (Participant 13)

“Sover omdat ek nou al klaar positiewe resultate gesien het, is dit vir my die moeite werd. Rêrig!” *[So far, because I already saw positive results, it was worth it for me. Really!]* (Participant 16)

“I discovered early on that my days off are actually better to do it because there were often moments when I had time completely alone. And nobody would come in and out you know, bothering me. I mean, even though I said to my kids: 'I am going to do my exercises now, please do not come into the room.' Because even when somebody just pops their head in I

felt my concentration shifts completely.” (Participant 17).

“Okay, vir my was dit nie baie lekker nie. Dit was vir my verskriklik frustrerend en irriterend. H’m, elke dag dieselfde min of meer dieselfde elke dag. So, ja, dit het nogal baie tyd uit my dag gevat en h’m, dit het op my senuwees gewerk as ek nie daarby uitkom nie. Dit sit in my agterkop. So ja, ek, dit was nie vir my vreeslik lekker nie. Maar ek het geweet ek moet klaarmaak.” *[Okay, I didn’t enjoy it that much. I found it very frustrating and irritating. Every day the same kind of thing. So yes, it took quite a bit of time out of my day and it played on my nerves if I didn’t get to it. It was at the back of my mind. So yes, I didn’t really enjoy it but knew that I had to finish it.]* (Participant 20)

“Aan die begin was dit obviously ’n lekker speletjie totdat ek dit toe die heeltid moes doen.” *[At the beginning it was a nice game until I had to do it all the time.]* (Participant 21)

“Ek het dit definitief geniet. Dit is miskien ’n klein bietjie verslawend.” *[I really enjoyed it. It maybe is a little bit addictive.]* (Participant 23)

“H’m, the intervention program I feel is really good. I, it was really well structured. H’m, like I, like I said it is really, the site is easy, I am happy that I could trace my training, my results and stuff like that. H’m, it’s also very responsive, like clicking and you know, the responses you get when you click.” (Participant 29)

“Well, you know, in the beginning obviously I was very very hopeful in terms of finding a solution to help manage the problem. H’m, and with the training, you know h’m, building a new routine to schedule this thing in and to understand the importance of doing that, and creating a routine and so on. And during the trial I felt h’m, much better about myself, and it’s not going to be an instinctive thing or something that I necessarily notice at first myself, h’m, but my boyfriend actually noticed, and he is like: ‘Are you pulling hair, because it doesn’t look like it?’” (Participant 31)

“Die rede hoekom dit nou vir my nie lekker was nie is omdat dit so moeilik was. En omdat ek dit so baie verkeerd kry en dan raak ek net kwaad vir myself.” *[The reason why I did not enjoy it, is because it was difficult. And because I got so many wrong and then just get angry at myself.]* (Participant 33)

“It was just a lot of the time, h’m, was just like yes, procrastination and other times I would be like, I got so much work to do. Got to do this as well. H’m, so it was kind of like, almost like mixed between the two of like yes, I don’t have to do work right now and I have got to do work now I have got to do this.” (Participant 34)

“H’m, ja, nee ek is ek is bly ek kan deel wees van die studie. Ek ek hoop maar h’m, daar kan iets positiefs daar uitkom. H’m, ja, dis, ja, vir myself ook, maar dan ook vir ander mense wat met dieselfde probleem sukkel.” *[Hmm, yes, I am glad that I was part of the study. I hope that something positive comes out of it. Yes, it is for myself as well, but also for other people that have difficulty with the same problem.]* (Participant 35)

“Ek meen, dis actually uitputtend soos die eerste paar keer wat ek dit gedoen het, was dit nogals mentally uitputtend en toe later dan raak jy meer gewoonnd daaraan en dan is dit nie meer so erg nie. Maar dis nog steeds, dit voel lank.” *[I mean, it is actually tiring the first few times I did it. It was mentally exhausted and then later I got more used to it and then it is not that bad. But still, it felt like a long time.]* (Participant 38)

“H’m en om verskille te kon sien, of nie, of selfs maar met die toetsie self te sit en dan ook te voel met sekere toetse om met sekere tye is ek verskriklik gefrustreerd en hoe ek ook so ‘perform’ waarin met sekere goed baie sleg daai dag en so, dit was, dit was ’n uitdaging om tydsgewys by die goed uit te kom.” *[Hmm and to see a difference, or not, or even just sit with the test and to feel more frustrated with certain tests and perform badly on that day. It was a*

big challenge regarding time, to get to everything.] (Participant 41)

Theme 2: Training Effects

The responses of participants training effects are summarised in the following section under the subthemes: 1) training effects on hair-pulling symptoms, and 2) other training effects.

Subtheme 1: Training Effects on Hair-pulling Symptoms

Participants were mostly unsure whether effects on pulling were due to the training program or whether they were just more aware of the pulling due to taking part in the research. The subjective feedback ranged from no change to positive benefit – mostly linked to being able to resist the urge or pull less. One participant reflected that there was an anticipation of withdrawal symptoms if not being able to pull. However, it was unsure what the participant meant by withdrawal. Training kept participants' hands busy and mentally pre-occupied, which reportedly helped not pull. A participant reported that training in the morning helped her not to pull during the rest of the day. Some participants' hair grew during the 5 weeks and they had to get used to other styles with longer hair. Those who did very well regarding lowering of pulling symptoms, were often very nervous that the pulling behaviour would increase when the training ended. For some participants, the symptoms did return after training.

Table 33 - Theme 2: Training effects - Subtheme 1: Training effects on hair-pulling symptoms

“Ek kan, ek kon nie agterkom dat daar ’n verbetering of ’n verswakking was nie. Dit, ek, ek... Dalk het dit, maar ek het nie aanvaar dat die twee ge’link’ het met mekaar nie.” [I cannot say whether there is an increase or decrease in symptoms. It, I, maybe it has, but I did not regard this change as linked to each other.] (Participant 03)

“My awareness is greater, so when I do it with one or two hairs I start freaking out much

more. I then stop. Maybe later when I am doing it again, then again, it's only one or two hairs. So, it's not just doing it the whole time and not being able to control myself. I think there is a degree of control somewhere, there is a feeling that comes and goes but I am able to control it better." (Participant 04)

"H'm, it was the same kind of sort, I don't know, almost seemed like a withdrawal symptom. So, I was constantly thinking about it, but I didn't have the urge. So even, I would be at home and think like now I, is the time where I would need to pull. But I didn't get up and do it because h'm, I didn't actually have the urge to, or a strong enough urge to... Ja, once I've no urge, just not strong enough to... H'm, so I don't know if that's just because it was distracting just the busyness of you know, of daily life and also how to fit in the training, and so I don't know if it's just this also distracting or if it was the training itself that's helping? H'm, then, ja, but I mean for most of the time h'm, any pulling that I did do was like very limited, so it would be like maybe, one or two that were out of place." (Participant 13)

"I do think, felt like it. Ja. I don't feel, I think h'm, other than the fact that I was conscious that I was on the training, and so you know where I was kind of feeling my hair, I was conscious that I was actually part of a training program. But I didn't feel like it has made any difference to my desire to do it." (Participant 19)

"I had to ask my dad, do you still see me do it because I don't realise if I'm doing it. He said, yes just in the evenings he noticed me picking. I do not think it's as bad, but I'm also not sure if it's just one of those break periods, where it stops and then just goes back down again." (Participant 30)

Subtheme 2: Other Training Effects Highlighted

Training also appeared to have led to various other areas being impacted. Some participants reported that they were recalling numbers more readily and felt less anxious. The fact that

the intervention is in the form of computer games, made some feel guilty that they are 'playing' instead of working or spending time with the family. Others enjoyed it, found the training interesting and felt it was nice to be able to contribute to information on HPD. A surprising outcome was that hair growing again and looking healthier, led to anxiety and pressure to disclose because friends and family would now comment on the participant's hair looking nicer. These participants did not necessarily tell people about the study or why their hair looked different. For other participants, being part of the study, disclosing and confiding to the researchers, made it easier to open to others about the hair-pulling. A participant who experienced benefit from the training, also reported that it was a relief that something other than medication was working – thus bypassing the negative side-effects of medication.

Table 34 - Theme 2: Training effects - Subtheme 2: Other training effects highlighted

"Because I work. So, for me it was always kind of a, it's the guilty feeling of here I am sitting, doing puzzles and I'm feeling like actually, I should be contributing to what's, to my job. So, from that point of view, it was just a mind shift of h'm, I shouldn't be doing what I am doing. Should be doing something else. It was a) structuring the time and b) sort out the emotions of should I be sitting and doing this?" (Participant 19)

"H'm, I mean, in the start it happened, right after Christmas it definitely helped to relax a bit. H'm, I think then maybe towards the end I was a bit, I was getting a bit more stressed trying to like actually find the time and then when I was doing it I was you know, I was kind of leaking into our evening time." (Participant 27)

"En h'm, ja, dit was goed om te sien dat my working memory darem verbeter het." [*And yes, it was good to see that my working memory improved.*] (Participant 35)

Contact 3: 3-month Follow-up Session - Reflection on Past 3 months and Process

29 interviews were included from the 3-month follow-up session (third contact or T3). During the third interview with the participant the question from which the interview flowed was:

“Tell me about the 3 months since you completed the cognitive training program?”

The 2 main themes identified are:

- Theme 1: Reflection on the past 3 months
- Theme 2: Take home message

Each of the main themes is divided into subthemes and supporting quotations from interviews are provided.

Theme 1: Reflection on the Past 3 months

The responses of participants regarding their experience the past 3 months since training completion are summarised in the following section under the subthemes: 1) hair-pulling during the 3 months, and 2) experience of not training anymore. Under each subtheme, the most relevant quotations will be shared.

Subtheme 1: Hair-pulling during the 3 months

Most participants reported pulling during stressful times over the three months since training ended. Those participants who had been on holiday, reported much less pulling during that time. There was a general theme that being part of the study created awareness of the condition, which to an extent appears to have discouraged participants from pulling. Overall, participants reported that after three to four weeks post-training, the pulling returned to baseline or was slightly better. Some participants reported that their family members were generally more in tune with the difficulties they were faced with daily.

Table 35 - Theme 1: Reflection on the past 3 months - Subtheme 1: Hair-pulling during the 3 months

<p>“Ek sou sê dit is minder. Want selfs h’m, toe ekke, jy weet, toe ek nou klaar is met my met my eksamens en so, dan het ek ook ’n bietjie flieks gekyk en dan is dit net dan ek het net nie so maklik hare uitgetrek nie.” <i>[I would say that it is less. Because when I, you know, when I was finished with my exams and so, I watched movies and it is just then, but then I did not pull hair so easily.]</i> (Participant 02)</p>
<p>“Because I haven’t been in a stressful situation. H’m, so ja. But I have noticed a difference regarding pulling hair. There was a period of like maybe two or three weeks where it started picking up again. Surely, I can’t, it was after the program. It was about maybe about a month after the program. Because I, in that, the month after I noticed I was really like I could even remove the urge easily. It wasn’t, the hair pulling wasn’t an issue for me.” (Participant 04)</p>
<p>“H’m, I wouldn’t say much happened. But I think that it h’m, I do think I probably, my hair pulling is less. I think I have been less aware of doing it. H’m, and then ja, I was sort of in a habit of doing it most of the time.” (Participant 06)</p>
<p>“En ek gaan nou kyk hoe lank dit uithou. En ek moet sê ek het dit het nogal goed gewees, gewerk vir ten minste twee na vier weke toe.” <i>[And I am going to see how long this last. And I must say that it was actually good, it worked for at least two to four weeks.]</i> (Participant 10)</p>
<p>“Well, I have not been pulling that much, I must say. It’s not as bad like it used to be.” (Participant 11)</p>
<p>“So, but my hair pulling has been appalling. Shocking! And I had a kind of, I had a kind of insight. Which I wasn’t sure if I shared with you? And that is that h’m, I was aware of two things. And the one was the times when there was a very strong compulsion to pull, which is</p>

almost impossible for me to resist. And the other times when I seem to be acting out of habit.” (Participant 12)

“So, the first, ja, two to three weeks were all good and then from there kind of h’m, didn’t h’m, couldn’t manage to kind of stick to not pulling.” (Participant 13)

“Ja. H’m, ja! Ek het vir ’n tyd lank na die ‘training’ h’m, dink ek het dit goed gegaan, spesifiek met die hare uittrek totdat daar spanningsvolle situasies ontstaan het. En ja, daarvandaan af besef ek net elke slag, dit is spanningsvolle situasies wat h’m, wat dit ‘trigger’.” *[Yes! I think for a long time after the training it went well, specifically with the hair-pulling until there were stressful situations that triggered it. And yes, from then on, I just realised that it was stressful situations that trigger it.]* (Participant 16)

“H’m, so I don’t think it’s been a huge difference in terms of h’m, you know, my obsession with my hair other than a heightened awareness of me doing it. I think that’s possibly the only real change in my behaviour. So, possibly that shortens you know, the sort of duration of me doing it h’m, but it doesn’t necessarily prevent me from doing it. You know I kind of still possibly do it, but in the process of doing it I am possibly more conscious of doing it. So, I think that’s really been the only change in the last three months.” (Participant 19)

“Okay, h’m, daar was ’n klein korterige fase wat ek gedink het: ‘Aha! Dinge begin nou beter raak!’ Dit het vir ’n kort rukkie wat ek omtrent geen, glad nie getrek het nie. Maar daarna het ek nog die heelyd getrek.” *[Okay, there was a short phase when I thought: ‘Aha things are starting to get better!’, but after that I have constantly pulled.]* (Participant 23)

“I don’t think it’s really changed, or it hasn’t improved in any way, so. I haven’t seen any, if anything maybe h’m, slightly worse now.” (Participant 27)

“I think it actually probably started again. It never really stopped. It was just less. And it

probably started again two and a half months ago or so. And it's pretty, I did not even know and the one day I was finished washing my hair and was I laying on the bed my mom says to me: 'What's going on with your head? Oh, my goodness.' And I went to look in the mirror and it was so bad." (Participant 30)

Subtheme 2: Experience of Not Training

Most participants were relieved that they did not have to train anymore, because of the extra time now available. A few said that initially, it was strange not to train but they then settled quickly into their old routine. Others missed the training and hoped there would be booster sessions during the 3 months. They were excited that they may be able to continue the training at the end of the 3 months break because they enjoyed doing something completely different during the day. One participant felt that when she stopped training, she very quickly returned to having no control over pulling.

Table 36 - Theme 1: Reflection on the past 3 months - Subtheme 2: Experience of not training

"It was it, ja it was just like a quite a sudden stop. I mean it would feel like: 'O, I need to be doing something today.' And then I would remember that I had completed it." (Participant 06)

"Het ek gedink h'm, het ek gedink dit gaan, ek gaan nou dit weer begin doen. Omdat ek nie dit nou, of omdat ek, vir my was dit as die ses weke of vyf weke net te kort." [*I thought that I wanted to do it again. I feel that six weeks or five weeks were just too short.*] (Participant 10)

"It's been fantastic not to train". (Participant 17)

"It did free up time in the evening, but the training was also quite fun to do. It was also fun because it was a break from work." (Participant 34)

Theme 2: Participant Take-home Message

The responses of participants regarding their take-home message at the end of the study are summarised in the following section.

Sharing their journey: Taking part in the study and talking to researchers about the difficulties, without judgment, reportedly began a journey for some participants towards being more open with others regarding their hair-pulling. Whether it was disclosing to people known to them or talking to strangers about the condition – in general, there was more acceptance of self and belief that they also had a story worth telling. They experienced support from friends and loved ones after disclosing, which meant a great deal to them. Participants emphasized that psycho-education and raising awareness were extremely important to lower stigma and created acceptance of HPD. Hair-pulling can be a minor ‘problem’ in the eyes of others but debilitating for the people living with the condition.

Randomization in groups: Some participants reported the fact that there was a control group and not knowing in which group they were randomized, tested motivation to continue training. Being part of something bigger than themselves, and having the researcher to answer to, made it easier to complete the study - even when not sure of the expected outcome post-intervention. Participants also said that experiencing success leads to increased self-confidence.

Responsibility: Most participants reflected that they realized if something was going to change regarding the pulling, they had to take responsibility for this. Some participants reported that taking time out of the day for self-care, something to nurture yourself was such an important part of recovery.

Table 37 - Theme 2: Participant take-home message

<p>“Dis, ek dink jy moet ook, jy moet jouself, jy moet dit wil doen.” <i>[I think you must, you have to want to do it for yourself.]</i> (Participant 02)</p>

“H’m, maar partykeer as ek nou gemaklik voel dan sal ek nou vir hulle sê: ‘H’m, ek trek my hare uit’ en dan dan sal ek nou weer die hele storie van vooraf verduidelik. So dit dit raak nogals, dit raak ‘pretty’ irriterend, maar h’m, ja, ek het net net weer daar besef soos jy weet, sy was nou nie ‘judgmental’ nie. Sy is soos: ‘O, dis awesome. Dis awesome dat jy aan studies deelneem.’ En jy weet, sulke tipe goed. So, so h’m, ja, ek h’m, soos mense weet ek het rêrig hulle weet nie wat dit is nie. En ek voel dat dat h’m, daar moet baie meer bewusmaking wees van dit. Ek weet net nie hoe nie, want dit is half so ‘awkward subject’ om op te bring.” *[But sometimes, if I feel comfortable then I will tell them I pull my hair and then I will have to tell the whole story from the beginning. So, it gets pretty irritating, but I just realised again, as you know, she was not judgmental. She said: O it is awesome that you are taking part in the studies. And you know, things like that, People don’t really know what it is, and I feel there should be much more awareness raised. I don’t know how, because it is such an awkward subject to raise.]* (Participant 02)

“I had a positive experience. I think it is definitely a good thing, because like I didn’t think people really understand or realize that something like this seems so minor but it’s so debilitating. It’s definitely something that you know, that the people who suffer from it h’m, it’s t’s major to us. So, you know to do a study like this is to find out why, what the reasons are and what the links are and how to improve it. It’s I think it is definitely a good thing.” (Participant 04)

“Ja. O wel, dit het tog positiewe uitkomstes gehad. Of dit nou ‘all in the mind’ was of nie, dit het, in ‘any case’ ’n positiewe uitkoms gehad so, ja, ek sal dit weer doen.” *[Ja, o well, it did have its positive outcomes. Whether it has been all in the mind or not, it did, in any case, have a positive outcome. So yes, I will do it again.]* (Participant 38)

“Ek het nogal, ja, want weet jy dit dit was in die een kant vir my h’m, vir my selfbeeld nie baie

goed nie, want ek het besef, weet jy my geheue, ek is, ek het geen probleem daarmee nie. Ek ek meen ek is 'n baie eerlik daaroor. Ek glo dit kom maar seker met die ouderdom ook, maar h'm, my geheue was, is maar nie wat dit moet wees nie. So, vir my selfbeeld was dit nie baie goed nie. Maar terselfde tyd het ek dit geniet. Dit was vir my lekker jy weet, dit het vir my gevoel dit stimuleer my." *[I have yes because you know that on the one hand, it was not great for my self-image, because I realised that with my memory I have no problems. I mean I am very honest about it. I believe it comes with age as well, but my memory is not what it is supposed to be. So, my self-image wasn't great. But at the same time, I enjoyed it. I really liked it, it felt like it stimulated me.]* (Participant 40)

Brief Chapter Overview

The chapter has provided an overview of participants' subjective experience of living with HPD – the impact it has on everyday functioning and on relationships with family, friends and in the work environment. The chapter also covered participants' experience of the training program, the effects thereof on hair-pulling, and what it was like to be a participant in the study.

Participants gave a valuable look into the life of a person with HPD – the challenges regarding various areas of functioning and family life. Participants indicated that CWMT was feasible and acceptable; furthermore, the intervention was associated with greater openness about symptoms at home, feeling less isolated, and feeling more supported.

In the next chapter, Chapter 7, the study findings will be discussed.

“H’m, the intervention program I feel is really good. I, it was really well structured. H’m, like I, like I said it is really, the site is easy, I am happy that I could trace my training, my results and stuff like that. H’m, it’s also very responsive, like clicking and you know, the responses you get when you click.”

Research Participant

Chapter 7: General Discussion and Conclusion

Introduction

The study compared the impact of cognitive working memory training (CWMT) and a control condition in a cohort of thirty participants (N=30) with a primary diagnosis of Hair-pulling Disorder (HPD). All included participants met DSM-5 criteria for HPD and had no comorbidities at baseline. Assessment of participants' general intellectual functioning suggested above average levels. Participants were randomly assigned to the cognitive training group (CTG, N=16) and the active control group (PG, N=14). Groups were matched for gender, age, ancestry, number of years of education, level of education and occupation. The ratio of female to male was 15:1 which is comparable to adult HPD literature (American Psychiatric Association, 2013a; Christenson, MacKenzie, & Mitchell, 1994; Lochner et al., 2005). Modalities that were the focus of assessment at the 3 different contact times were hair-pulling symptoms (HPS), working memory (WM), as well as impulse control (IC) and emotional regulation (ER).

The three aims posed at the start of the study were whether cognitive working memory training (CWMT) would 1) be efficacious for reducing the symptoms of HPD, 2) improve compromised neurocognitive functions, 3) and be experienced by HPD patients as an acceptable and feasible method of intervention.

The findings of this study established that the CWMT method utilized here was associated with a significant reduction in HPS at 5 weeks and 3 months, as well as increased WM at 5 weeks. IC and ER were not significantly different in HPD at baseline and did not change with treatment. These findings suggest that an internet-based CWMT intervention, done at participants' homes, could be feasible as a mode of treatment for HPD. The study had an 83% retention rate, which supports the argument about the feasibility and acceptability of a CWMT, more specifically Cogmed in this case, as a treatment option for HPD.

In the next section, the main findings will be considered in more detail, focusing on the three research aims stated at the outset. The results will be brought into context with existing literature, followed by a discussion of study limitations and future directions.

Main Findings

Research Aim 1: Cognitive Working Memory Training Effect on Hair-pulling Severity

Hair-pulling Severity

MGH-HPS total scores indicated that, compared to the control intervention, CWMT lead to a significant decrease in HPS. 5 weeks of cognitive training, with the reduction maintained at 3-month follow-up. The PG did not show significant changes in HPS over time and severity of HPS remained '*moderate*'. The only significant difference in HPS between CTG and PG, however, was immediately after training when CTG presented with a significant decrease in HPS compared to PG.

General Functioning

Initially CGI-S ratings were in the '*slightly ill to moderately ill*' range for both CTG and PG. There was no significant difference between CTG and PG in the CGI-I at 5 weeks, with both groups demonstrating some improvements.

The slight discrepancy in findings between the data rendered by the two illness severity measurement scales, i.e. MGH-HPS and CGI, deserves discussion. The results for the MGH-HPS suggest benefit for CWMT for HPS whereas the CGI did not suggest this. Firstly, the different finding may be due to the MGH-HPS being a self-report scale (Keuthen et al., 1995) and CGI a clinician report scale (Guy, 1976). In addition, these scales also measure slightly different constructs. MGH-HPS is a scale developed for measuring HPS in particular, thus giving a more detailed and accurate description of hair-pulling symptoms. CGI, on the other hand, was developed to look at the illness severity/general functioning and improvement of any illness pre- and post-intervention, and thus not specifically developed for HPD. It is also important to note that the CGI-I score is general reflection of how the person

is functioning at present and their current mental state, which can also be influenced by many factors other than the illness. The CGI-score could also have been impacted by the fact that the PhD candidate was not blinded to group randomization. For these reasons, it is argued that in this context, the findings of the MGH-HPS, as the primary outcome measure, are a more accurate reflection of change in HPS.

Before looking at the maintenance of reduction in hair-pulling symptoms, it is important to highlight the novelty of the current findings, i.e. the reduction in hair-pulling symptoms, at 5 weeks immediately post-training. As far as we know, this is the first time that a working memory training program has been utilized in the treatment of HPD. The results are consistent with previous work using cognitive training in disorders associated with impulse control difficulties such as substance use disorder, anorexia nervosa, ADHD and emotional dysregulation (Brooks, Funk, Young, & Schiöth, 2017; Klingberg, 2010; Klingberg et al., 2005; Roughan & Hadwin, 2011; Schweizer et al., 2013).

Turning our attention to the maintenance of treatment gain, few studies have shown maintenance of treatment effects at 3 months or longer follow-up (Keuthen et al., 2011; Keuthen & Sprich, 2012; Twohig & Woods, 2004; Woods & Miltenberger, 2006). The current CWMT study's finding of maintenance of gain at 3-months follow-up are thus particularly encouraging.

Impairment

The levels of impairment in functioning at baseline, immediately after training, and at 3-month follow-up were similar in both groups. Work impairment due to HPD remained unchanged over time for both groups and was mild to none. However, both these groups showed a significant reduction in impairment in the social domain due to HPD, from the '*higher end of mild*' to the '*lower end of mild*' impairment immediately after training and remained as such at 3-month follow-up. Participants in the CTG specifically reported significantly reduced disability from '*mild*' to the '*lower end of mild*' in terms of family

relationships from before training to 3-months after training was completed. So, in summary, individuals in the CTG reported reduced impairment, in the social and family domains, from baseline to the end of the study. Impairment in the social domain reduced significantly in the group receiving the control intervention.

At baseline, impairment due to HPD was greater in the family and social context than the work environment for both CTG and PG. This was also seen in other treatment effect studies, which highlighted that very often the work environment is less intimate and thus leads to fewer feelings of guilt linked to hair-pulling behaviour and accompanied secrecy (e.g. Tung et al., 2015). Impairment in the social context decreased significantly for both study groups. Arguably, the opportunity to speak about their symptoms and feelings lowered the perceived stigma, embarrassment and feelings of shame. Participating in the study may have also contributed to increased openness, disclosing more readily and in feeling more supported. The same may be true for family relationships – participating in the training takes many hours which likely led to conversations about HPD within the family environment. Significant others may have learnt of the distress and impairment caused by HPD for the first time. Lowered impairment in the family and social domains may explain the reduced functional impairment reported by most participants. Because of the professional stance usually maintained in the work environment, the above hypotheses probably do not apply to disclosure to colleagues and thus might be the reason for work impairment due to HPD remaining low and constant over the trial period.

Once again, the issue of why the change in MGH-HPS results were not significantly associated with general impairment in functioning as measured by the SDS, warrants comment. As mentioned previously, MGH-HPS was developed specifically to assess hair-pulling symptoms, whereas the SDS looks at the impairment caused by any illness. MGH-HPS might also pick up more subtle positive changes not measured by the SDS.

Research Aim 2: Cognitive Working Memory Training Effect on Working Memory, Impulse Control and Emotional Regulation

Working Memory

On a WM task, WAIS-III LNS, which includes switching between letters and numbers, WM was ‘average’ and remained similar between CTG and PG at all the contact times. For the CTG and PG respectively, there were also no significant changes between the contact times. On a more basic WM task, WAIS-III DS, repeating number lists backwards and forwards, it was found that the CTG had significant gain immediately after training compared to the PG. However, this gain was not maintained at 3-month follow-up. PG gradually improved and showed significant improvement from pre-intervention to the 3-months follow-up. However, WM was similar in range and scored as ‘average’ for CTG and PG at all the contact times.

These above-mentioned findings could possibly be a signal of the mechanism by which the intervention worked, which may require future investigation, but may also have other explanations. Although WM impairment was anticipated (Chamberlain, Fineberg, et al., 2007; Slikboer et al., 2018; Stanley, Hannay, & Breckenridge, 1997), none of the participants had significant difficulty in WM at baseline, with WAIS-LNS and WAIS-DS scores suggesting average performance, compared to norms. Notably, most of the participants were *above* average in terms of their general level of intellectual functioning. It may be argued then that their WM should have been above average as well. Thus, in relation to their own cognitive functioning, both groups probably performed worse on WM than would be expected.

When taking a closer look at the subtests, the more complex assessment of WM, WAIS-III LNS, measures the ability for working memory, attention and mental control, while the more basic WM assessment, WAIS-III DS, measures auditory working memory, attention, encoding and auditory processing (Wechsler, 1997). Crowe (2000) found that although basic digits forwards and backwards contribute to performance on WAIS-III LNS, it also contains components of processing speed and visual-spatial functions and warns against linking poor

performance solely to auditory processes. In a study looking at delay discounting and WM, although delay discounting decreased, the results for WAIS-III LNS showed no significant change from pre- to post-intervention (Bickel et al., 2011), which is similar to what was seen in this study. The authors further linked this finding to the WAIS-III LNS' lack of sensitivity, only detecting large changes in performance, as well as working memory training not necessarily improving working memory performance (Bickel et al., 2011). The WAIS-III DS has also been described as a test with poor face validity due to its low complexity, whereas WAIS-III LNS' face value is much higher, but showed that simpler WM tasks can be roughly equivalent to more complex tasks (Hill et al., 2010; Unsworth & Engle, 2006).

In an attempt to counter practice effect as best possible, a delay in retest was built in (Lemay, Bédard, Rouleau, & Gilbert Tremblay, 2004) and follow-up assessment took place at 5 weeks and 3 month time intervals. This study's findings are consistent with results from a meta-analysis of working memory training programs (Melby-Lervåg & Hulme, 2012). The meta-analysis indicated that after training, working memory shows short-term improvement, but the improvement is not sustained in the long-term. The meta-analysis further highlighted the fact that working memory training appears to benefit specific tasks which the participant was trained in and does not lead to modality-free executive improvement (Melby-Lervåg & Hulme, 2012). Similarly, in a study investigating CWMT, only a digit span task showed improvement post-intervention. It thus does not seem that CWMT improves performance on unrelated tasks or that it enhances cognitive modalities in general (Etherton et al., 2018). These findings thus correspond to the results of the current study – that there is an increase in performance on WM tasks that closely match the training tasks, but this is not sustained in the long-term.

Impulse Control

On the BISS-11, motor impulsiveness and non-planning impulsiveness were similar between CTG and PG at all contact times and were '*average*'. In CTG and PG respectively, there was also no significant change from pre- to post-intervention and 3-month follow-up. Attentional

impulsiveness remained '*average*' when CTG and PG were compared at the various contact times. However, although still in the '*average*' range, CTG presented with a significant reduction from pre-intervention to 3-month follow-up.

Cognitive interference, as assessed by the SCWT-A, showed no significant differences between CTG and PG pre-, post or 3 months after the training. However, both PG and CTG increased in their ability to counter interference from '*average*' to '*high average*' from pre- to post-intervention and maintained the gain at 3-month follow-up.

Regarding motor and planning components of impulse control, both groups' ability tested '*average*' compared to the general population and did not change after training for either of the groups. The former, i.e. controlling motor responses and cancelling once busy pulling were impaired for HPD patients (Stanley, Hannay, et al., 1997; Chamberlain, Fineberg, et al., 2006; Odlaug, Chamberlain, Derbyshire, Leppink, & Grant, 2014b), whereas this was not seen in both groups on this specific assessment, but rather was consistent with prior work noting that motor inhibition was normal in HPD (Bohne et al., 2008; Chamberlain et al., 2007). The finding was also in line with limited difficulty found in the inhibitory deficits/response impulsivity on another study of HPD, PSP and HC (Grant, Odlaug, & Chamberlain, 2011). Attentional impulsiveness, also measured '*average*', did, however, improve significantly on the CWMT from the start to the end of the study, but not immediately after the intervention. The first-order factor that seems to have improved in this regard was attention. Perhaps increase in WM ability set the stage for better ability for attention, as ability to pay attention and WM is closely related (Awh, Vogel, & Oh, 2006).

The finding of average IC in both participant groups stands in contrast to the literature where multiple studies highlighted IC difficulty in HPD (Chamberlain, Blackwell, Fineberg, Robbins, & Sahakian, 2006; Chamberlain, Fineberg, Blackwell, Robbins, & Sahakian, 2006; Stein, Simeon, Cohen, & Hollander, 1995; Stein et al., 2010; Wetterneck, Lee, Flessner, Leonard, & Woods, 2016). Cognitive interference was not impaired in the participant groups, which

was consistent with some prior work (Coetzer & Stein, 1999), but inconsistent with other findings (Van Velzen, Vriend, De Wit, & Van den Heuvel, 2014). Although delay in retest was implemented, increased performance on attention tasks may have been due to a practice effect as both groups did significantly better post-intervention. Lemay et al. (2004) previously noted a practice effect in adult participants (52 to 80 years) on the Stroop Interference scale.

Emotional Regulation

As measured by the ARS, the ability to control emotions were reported to be possible '*half of the time*' by the both groups and they believed that '*sometimes*' there was a causal link between emotions and hair-pulling. This finding was similar between CTG and PG at all three the contact times. In CTG and PG respectively, the only significant change was for PG from baseline to 3-month follow-up, showing less confidence in the causal link between emotions and hair-pulling.

When considering the DERS subscales, emotional impulse control difficulty showed a decrease in PG from '*about half the time*' before training to '*sometimes*' at 3-month follow-up. However, CTG and PG did not present with significant differences at the various contact times. Lastly, limited access to effective emotional regulation strategies was also similar between CTG and PG at all contact times and was reported to be present '*about half of the time*'. However, PG presented with significantly less difficulty immediately after 5-week training which was maintained at 3-month follow-up. Lack of emotional awareness and emotional clarity, difficulty engaging in goal-directed behaviour, as well as non-acceptance of emotional responses were all similar between CTG and PG, at all contact times and reflected having difficulties in these areas '*about half of the time*'. These findings are consistent with previous work indicating that participants' own perceived control over hair-pulling, were impaired in comparison to controls (Keuthen, Savage, O'Sullivan, et al., 1996), as well as a study where BFRBs as a group, were shown to struggle with emotional clarity, IC, access to ER strategies and 'snapping out' of the emotions (Roberts, O'Connor, Aardema, Bélanger, & Courchesne, 2016).

In summary, the above section reflected on the various cognitive functions that were expected to improve with CWMT. Our findings are consistent with recent studies in cohorts of healthy college undergraduates and young adults, which found that performance on WM, attention, fluid intelligence and executive functioning, that were not directly trained by Cogmed, were not improved (Etherton et al., 2018; Redick et al., 2013). The meta-analysis concluded that the generalizability of CWMT is thus rather limited. While not all data are consistent (Shinaver, Entwistle, & Söderqvist, 2014), our findings support this conclusion and are consistent with the hypothesis that WM plays a key role in mediating the impact of CWMT.

Research Aim 3: Participants' Subjective Experience of Living with HPD, Cognitive Training and Taking Part in a Research Project

Life with Hair-pulling Disorder

Various themes were highlighted about life with HPD, and how things would be different without HPD. These themes included a) Hair-pulling experience, divided into triggers and pulling behaviours, the onset of HPD, immediate impact of hair-pulling and insight into the behaviour; b) Emotions prior/leading to pulling, as well as emotions during/after/and or because of hair-pulling; c) Relationships, including: family of origin, the role of partners, siblings, children, the community and hair-stylist; d) Interventions tried and tested regarding self-help strategies, medication, psychotherapy and a reflection on ineffective outcomes; and lastly e) a reflection on the Self: beliefs, the impact of being unaware what the behaviour is, other BFRBs or OCD-like acts and what they imagine life without HPD would be like.

Participants reported many situational triggers, similar to what has been shown in the literature (Casati et al., 2000; Johnson & El-Alfy, 2016; Whitaker et al., 2003). Controlling pulling urges were reported to be somewhat easier when amongst others. Many reported that there was a time in their life when the pulling was less, but never gone completely. Some ambivalence was noted on whether they really want to stop the behaviour. It was also clear that there were many sites and ways of hair-pulling, and that HPD symptoms differ

amongst individuals. The age of onset varied but was mostly linked to childhood and/or adolescence, similar as literature has shown (Christenson, MacKenzie, & Mitchell, 1991; Cohen et al., 1995; Lochner et al., 2005; Walsh & McDougle, 2001; Winchel, 1992). Situations (events, traumas or people) participants felt might have been instrumental in the start the behaviour were also diverse. Many of the theoretical models discussed earlier were reflected in participants' understanding of HPD etiology, like the Ethological model (Swedo, 1989; Swedo & Rapoport, 1991), Biopsychosocial model (Franklin et al., 2006), Cognitive Control Model (Stein, Chamberlain, & Fineberg, 2006), Affective dysregulation model (Flessner, Knopik, & McGeary, 2012; Keuthen et al., 2010; Shusterman, Feld, Baer, & Keuthen, 2009), Stimulus regulation model (Penzel, 2018), and Comprehensive Model of TTM (Mansueto et al., 1999).

The immediate impact of pulling was mainly linked to hairstyling, the amount of time spent pulling as well as avoidance of various activities because of the damage that was done and difficulty keeping the damage hidden. Participants presented with different levels of insight regarding their pulling behaviour. Emotions played a significant role in the pulling experience, and many participants reported negative and challenging emotions prior, leading, after and/or because of the behaviour. There were some reports of neutral and positive emotions linked to pulling, but in general, the sense of being trapped in an emotional pulling cycle was a theme that presented strongly. Many of these themes were echoed by previous studies – the negative impact of HPD (Harvard Health Commentaries, 2007; Seedat & Stein, 1998; Tung et al., 2015; Woods, Wetterneck, et al., 2006) linked to negative affect and control difficulty (Casati et al., 2000; Johnson & El-Alfy, 2016; Whitaker et al., 2003).

Consistent with previous work (Diefenbach, Mouton-Odum, & Stanley, 2002; Seedat & Stein, 1998; Stemberger, Thomas, Mansueto, & Carter, 2000), relationships varied greatly in what role they played in the participants' management of the HPD. Most of the time, there was an awareness of the impact that pulling may have in these environments. Participants reflected

on their family of origin, their current family, the community, colleagues and friends, as well as highlighting the importance of their hairstylist. Many times, other family members were reported to also present with hair-pulling or other BFRBs.

Various interventions were highlighted, from self-help attempts to find information on the internet, using non-pulling and hair-styling strategies, to receiving diagnostic clarity and trying medication and psychotherapy. Most participants could relate to ineffective outcomes and how frustrating it was for yet another intervention to fail. Some participants reflected on first line pharmacotherapy to have been anti-depressants, but with little effect – as was also reflected in the literature (Rothbart et al., 2013; Streichenwein & Thornby, 1995; Van Minnen, Hoogduin, Keijsers, Hellenbrand, & Hendriks, 2003). Various therapies were also part of intervention for many participants, and although CBT was mentioned, HRT and DBT or ACT-enhanced HRT did not seem to be treatment of choice of South African psychotherapists, as is the case in more current international literature (Azrin, Nunn, & Frantz, 1980; Bloch et al., 2007; Keuthen et al., 2011, 2012; Twohig & Woods, 2004; Woods et al., 2006)

Self-reflection showed that participants have many beliefs regarding the pulling and what the implications are for their personal characteristics. Receiving a diagnosis or gaining more knowledge about the condition came with such a sense of relief for most participants. A few also presented with other BFRB or OCD-like acts. In the literature many co-morbid difficulties were reported (Christenson et al., 1994; Houghton et al., 2016; Winchel et al., 1992), many of which might arise due to not seeking assistance when HPD started initially (Adaletli et al., 2016). In general, participants reported that life without HPD would be much the same but with improved self-esteem, confidence and more time to engage in life.

Experience of Cognitive Training and Study Participation

When participants were asked about their experience of the training and being part of the study, they commented on their training commitment and subjective training experience, as

well as training effects on hair-pulling, and other areas they have noticed might link to the training.

The commitment participants made at the outset of the study, were reportedly what motivated them to conclude the training. In both groups, most participants felt that the training instructions were easy to follow and initially the training was interesting. As the training continued, many reported it became tedious and more like a task. The CTG participants commented negatively on the fact that there were many repetitions of the same tasks, PG participants reported 'building puzzles' as a highlight of their day. They commented that they found it relaxing, in contrast to many individuals in the CTG who reported experiencing anxiety to perform well. In general, participants felt proud that they completed the program and acknowledged that it was really important to plan very carefully exactly when training sessions are going to take place and stick to the schedule as far as possible. There was uncertainty amongst participants whether gains were because of the training or because of raised awareness of the hair-pulling as a byproduct of taking part in the study. Those participants who saw a positive effect on hair-pulling symptoms were generally nervous that the pulling behaviour might return when the training stopped. Other effects of the training that were highlighted by participants varied – from recalling numbers more easily, to feelings of relaxation or even guilt for playing 'games' and more readily disclosing HPD to others.

Reflection on the Process

Lastly, on reflection of the process at 3-month follow-up, there was mention of what happened in the past 3 months, what it was like not to have to train anymore and general reflection on taking part in the study.

Most participants reported pulling during stressful times and pulling less during times when they were on holiday in the past 3 months. In general, it seemed that pulling either returned to baseline or was slightly better than initially reported. Some participants reflected that it was strange not to train anymore, whereas others welcomed not training. Those who found

benefit reported feeling anxious that symptoms might return when training stopped. They also reflected that the study provided the opportunity to open up about the secret and share their journey with the researchers. This, in turn, made it easier to disclose to others and gain more support which was often unexpected. The impact of knowing they were randomized into a group but not knowing which one, reportedly tested their motivation to complete the program at times. Lastly, some participants reflected that they realized the responsibility lies with them to change the behaviour and that it is going to take work and commitment.

As mentioned previously, it is fairly infrequent that qualitative data is included as part of RCTs. However, in this study it made a significant contribution to understanding HPD, as well as the experience of training and being a participant in this research. It provided space for the voice of participants, giving them the opportunity to be heard through words, sharing their thoughts, feelings, ideas and life experiences.

Limitations

Several study limitations deserve emphasis. Firstly, the sample size was small and there was limited statistical power which might lead to type II errors. With a larger sample size, some differences may have reached statistical significance. Although it was hoped to include 20 participants in each group, time and cost restrictions capped the participation number at 30 in total. However, the sample size was still on par with other intervention studies and reports of meta-analysis focusing on HPD (Falkenstein et al., 2015; Grant et al., 2014; Keuthen et al., 2012; McGuire et al., 2014; Rehm et al., 2015) and WM (Bickel et al., 2011; Brooks et al., 2016; Etherton et al., 2018; Jolles et al., 2013; Roughan & Hadwin, 2011; Vogt et al., 2009) and had sufficient power to demonstrate significant changes on the MGH-HPS at 5 weeks.

Secondly, participants included are not fully representative of the population of individuals with HPD; as there were strict exclusion criteria of no substance use history, no recent treatment changes and no psychiatric comorbidity. The latter makes it somewhat easier to

measure outcomes but may not be entirely generalizable to a real-life clinical setting. The male: female ratio was representative of the current prevalence rates seen in the literature but were not powered to look at subsamples e.g. just males. Participants responded to advertisements for research and were thus treatment seeking from the onset. It is thus unclear how participants would engage in the program if they did not necessarily seek out treatment themselves.

Thirdly, the PhD candidate was not blind to participant group randomization, so although research contact was relatively consistent for all participants, there might have been subtle variation in approach, depending on group inclusion. Although there were both self-report and clinician report instruments, face-to-face interviewing often leads to underreporting as well as not getting access to very serious cases as one might come across in an online HPD study (Bottesi et al., 2016). The mixed-method single blind approach might have led to some researcher bias, i.e. scoring the CGI on follow-up sessions or subtle differences in conducting clinical interviews. This could have been prevented if a mixed-method double-blind approach was utilized. The strength, however, is that the same researcher saw the participants for all their contact times which keeps variables outside of study consideration to a minimum.

Fourthly, with regards to the intervention, five weeks was a relatively short treatment regime and no booster sessions were offered as part of the treatment. However, treatment length was based on the research protocol for Cogmed, which is well researched and because of its focus on WM tasks, was ideal to address the aims of the study. It is an expensive program, which might be a limitation in rolling it out as a treatment of choice in general.

In conclusion, we found that CWMT significantly reduced HPS over time, and improved WM in the short-term but not long-term, and may be an alternative to the few existing evidence-based treatments for HPD. The control condition did not have any impact on HPD or its associated neurocognitive deficits. Both conditions improved participant engagement in social and family functioning, and both conditions were reported as being user-friendly with

clear instructions. The findings thus render CWMT as a feasible and acceptable intervention in general. Taking into account that South Africa is a low to middle income country – the question is posed whether the intervention is also accessible and affordable.

With regards to accessibility, participants to the study communicated that the program was readily accessible and easy to follow for the 5 weeks if you had access to a computer with internet. Participants did not have to pay for the intervention out of pocket, as it was subsidized by the study funding. For anyone deciding to complete the program, it will currently cost approximately R7 000, which includes contact time and support from the coach. Although this may appear expensive, it is still considerably less than costs associated with an adequate number of traditional clinical psychology sessions in South Africa, for example. Considering that the Cogmed program consists of 25 sessions, as well as coach check-ins and guidance, compared to weekly one-on-one sessions one would expect from traditional psychotherapeutic treatments, while possibly also augmenting with medication, puts the affordability of Cogmed into perspective.

Despite these limitations, we believe that the study findings add valuable information to the fields of HPD, WM and CT, and that it paves the way for future studies

Future Directions

The Cogmed protocol used here was the standard research protocol used for investigating the effect of Cogmed on various disorders. Improvements due to CWMT were maintained at 3 months but it would be valuable to follow these changes up in the longer run, e.g. over 6 or 12 months. Investigating a program with longer duration, more sessions or booster sessions after completion of training, might also be avenues for future research. CWMT may also be used to boost other therapeutic modalities, either psychotherapy or psychopharmacology. In future, cognitive training programs other than Cogmed, which may be more readily accessible, should be explored. Adapting the research protocol for children and adolescents,

might also be a future research path, especially because childhood onset of HPD is the norm.

Future studies might turn attention to investigating relevant underlying mechanisms by using neuroimaging functional magnetic resonance imaging (fMRI) during WM tasks, or alternatively examine neuroimaging pre- and post-intervention using resting state MRI (rs-fMRI) or other functional neuroimaging techniques that are able to assess connectivity across brain regions. It is possible that genetic differences in WM could play a role in determining which individuals are more responsive to interventions that focus on improving WM.

In the future, larger pragmatic RCTs could be employed, *relaxing* the inclusion criteria to include comorbid disorders. Such trials could also investigate CWMT in the absence of coach or psychologist support, as the explanatory design of the current study included coach check-in which may not be as available in real life contexts. Larger sample sizes might be recruited if the research design does not require face-to-face contact, and data can be gathered telephonically, via e-mail or online. Cost-effectiveness of the different treatment options available for HPD should also be determined. For example, on the basis of the novel findings here that there is benefit in CWMT training for HPD, it would be valuable to compare the scale-up and cost-efficiency of different delivery methods for WM training.

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Addendum 4: Abbreviations

3-month follow-up assessment	T3
Acceptance and Commitment Therapy	ACT
Attention-deficit Hyperactivity Disorder	ADHD
Affective Regulation Scale	ARS
Barratt Impulsiveness Scale	BIS-11
Behaviour Therapy	BT
Body-focused Repetitive Behaviour	BFRB
Clinical Global Impression Scale – Improvement	CGI-I
Clinical Global Impression Scale – Severity	CGI-S
Cogmed Working Memory Training	Cogmed
Cognitive Working Memory Training	CWMT
Cognitive Behavioural Therapy	CBT
Cognitive Training	CT
Cognitive Training Group	CTG
Comprehensive Behavioural Model	ComB
Computerized Cognitive Training	CCT
Diagnostic and Statistical Manual of Mental Disorders (5 th Edition)	DSM-5
Dialectical Behaviour Therapy	DBT
Difficulty in Emotional Regulation Scale	DEERS
Doctor of Philosophy	PhD
Expanded Structured Clinical Interview for DSM-5 for Obsessive Compulsive Spectrum Disorders	SCID-OCSD-11
Food and Drug Administration	FDA
Habit Reversal Training	HRT

Hair-pulling Disorder (Trichotillomania)	HPD
Hair-pulling Severity	HPS
Immediate post-intervention assessment	T2
Major Depressive Disorder	MDD
Massachusetts General Hospital - Hair-pulling Scale	MGH-HPS
Metacognitive Techniques	MCT
N-Acetylcysteine	NaC
Obsessive-Compulsive and Related Disorders	OCRD
Obsessive-compulsive Disorder	OCD
Control Group	PG
Pre-intervention / screening assessment	T1
Progressive Muscle Relaxation	PMR
Qualitative Questionnaire	QQ
Randomized Controlled Trial	RCT
Selective Serotonin Reuptake Inhibitor	SSRI
Sheehan Disability Scale	SDS
South Africa	SA
Stimulus Regulation Model	SR
Stellenbosch University	SU
Stroop Color and Word Test – Adult Version	SCWT-A
Trichotillomania	TTM
Trichotillomania Learning Center-Scientific Advisory Board	TLC-SAB
Wechsler Abbreviated Scale of Intelligence	WASI
Working Memory	WM
World-wide-web or Internet	www